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ABSTRACT

This monograph on international disability issues offers three main papers giving English, Australian, and New Zealand viewpoints. The first paper is by Len Barton from England and is titled "Disability and the Necessity for a Socio-Political Perspective." Barton attacks the medical model of disability and argues that people with disabilities ought to change the political discourse about disability to one involving rights and choices tied to political action. He urges them to develop a political and social movement to further their ends. Keith Ballard comments on Barton's paper in "A Socio-Political Perspective on Disability: A Comment from the New Zealand Context" and relates it to the mainstreaming debate in education. He compares the stigmatization of children with disabilities to that of the Maori minority in New Zealand and calls for a public discourse that includes the voices of all oppressed groups. In "Pigs' Tails and Peer Workers, the View from Victoria, Australia," Gillian Fulcher critically discusses the "economic rationalist" discourse of the Australian welfare state and cautions that the formal rationality of political rights may not result in effective change. Commentaries from U.S. individuals are then presented by Joseph Stubbins, Margaret A. Nosek, Frank Bowe, Mary Ann Carroll, James Charlton, David Pfeiffer, and Hugh Gregory Gallagher. A final rejoinder by Barton completes the monograph. Each paper contains references. (DB)

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Disability and the Necessity for a Socio-Political Perspective

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The International Exchange of Experts and Information in Rehabilitation

UNIVERSITY OF NEW HAMPSHIRE

World Rehabilitation Fund

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Monograph #51

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Disability and The Necessity for a Socio-Political Perspective

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with Commentators
United States

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Preface and Acknowledgements

The International Exchange of Experts and Information in Rehabilitation (IEEIR) is a project funded through the National Institute for Disability and Rehabilitation Research (NIDRR) to import knowledge from other countries and to make that information about disability issues coming from other countries available to U.S. audiences in written form through monographs, fellowship reports and newsletters. Our project design allows us to provide some travel funds to a foreign IEEIR author, or potential author to travel to the U.S. Len Barton was such an individual selected in 1991 to visit the U.S. and to participate in the Society for Disability Studies (SDS) meeting in Oakland, California, to share a British perspective. To participate in that same SDS meeting, and IEEIR forum: *The Changing Nature of Disability Awareness Worldwide*, the IEEIR also partially supported Xu Yun from China and Tri Setiono from Bandung, Indonesia.

Since the IEEIR focuses its efforts on Asia and the Pacific, as well as Africa, (the IDEAS project supports exchanges with Europe), Len Barton engaged for us two social policy researchers from Australia and from New Zealand (Keith Ballard and Gillian Fulcher) to prepare commentaries and responses to his work. This brought in one area of the world that the IEEIR sets up exchanges with. However, we are very much aware that we have included only the English-speaking part of the world and that is a practice we would ordinarily not wish to follow. We do apologize. We know that this monograph would look much different, if, let's say, we had included perspectives from India and Africa. In a sense, we in the so-called developed world are actually quite privileged to be able to engage in the type of discussion and debate which is presented in this monograph.

After receiving the three pieces from our English-speaking overseas colleagues, we then wanted to get another perspective at least from a U.S. standpoint and asked several individuals to prepare responses to the initial three pieces. The individuals whose commentaries you will be reading here were selected because of either their academic or practical interest in the socio-political realm relevant to disability. Six of these commentators have disabilities so that they bring that experience to their comments as well, and five of them have had fellowships through the IEEIR so they also have an international, and an IEEIR perspective. We acknowledge with great appreciation all of these people who took the time, interest and care to react to the British, New Zealand and Australian chapters.

As one of the commentators, Stubbins points out in his commentary,

"Barton's conflict theory of society may be a useful analytic device, but he has given few strategies that would build a strong constituency to produce the liberation of disabled persons. How would we raise the money and win the support of public spirited citizens? How would we go about building coalitions with similarly disadvantaged constituencies?"

And as Pfieffer also makes clear, "...being disabled is no reason for other persons to treat [us] in a harmful manner. In the United States (and I can infer in the United Kingdom, New Zealand, Australia, and many other nations) disabled people are devalued and treated in an oppressive way. [They] tend to internalize that oppression and feel guilty for it. [They] then begin to act in a way which legitimizes the oppression and the cycle continues."

Most of the commentaries address these concerns and points of view from various angles, as does the exceptional foreword by Richard K. Scotch. Scotch, Associate Professor of Sociology and Political Economy at the University of Texas at Dallas, is the author of a book, *From Good Will to Civil Rights: Transforming Federal Disability Policy*, and numerous articles on disability policy, the disability rights movement, and the reform of social policy. In 1984 he received a World Rehabilitation Fund, IEEIR fellowship to study disability policy in Great Britain.

We hope that by sharing this mix of perspectives and points of view through the monograph format we will provide material for many other constructive forums for not only *discussing* the politics of disability, but *addressing* current needs and *developing* strategies around the world. We invite you the reader to comment and to be a part of this process.

Finally, we wish to acknowledge with gratitude the National Institute of Disability and Rehabilitation Research, William Graves, Paul Ackerman, and Ellen Blasiotti, without whose support all of this would not be possible.

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June 1992

Foreword

For the past quarter century, disability advocates have used a variety of metaphors and analytic frameworks to convey a basic idea - that the prevailing paradigm of disability in the service delivery system and society at large was flawed and harmful to people who have disabilities. The paradigm under criticism was one that defined disability and the person who experienced it in medical or clinical terms, and further assumed that the implication of having a disabling condition was inherently isolating from the societal mainstream, usually with psychosocially pathological consequences which required professional treatment, and was typically either tragic or ennobling. In such a paradigm, the implied intervention was one of rehabilitating the individual with the disability, medically, psychologically, socially, and vocationally, to enable them some approximation of a "normal" life. Critics of this paradigm such as tenBroek, Bowe, Hahn, and Oliver, have proposed an alternative view in which a physical or mental impairment is not inherently handicapping but rather becomes so as the result of prejudice and political disadvantage. Such critiques have been embodied in the works of the many organizations and individuals comprising the disability rights and independent living movements in the United States, and similar groups operating across the world.

Barton, Fulcher, and Ballard each call for a socio-political perspective on disability, but in doing so they are walking on a well travelled path. In "Disability and The Necessity for a Socio-Political Perspective," Len Barton attacks the medical model of disability and argues that people with disabilities have been explicitly excluded from "official" and academic discourse concerning disability, symptomatic of their lack of political power. He argues that people with disabilities ought to change the political discourse about disability to one involving rights and choices that is tied to political action. He concludes by calling for the development of a political and social movement of people with disabilities that seeks political goals and brings their voices into public discourse over disability.

Keith Ballard, commenting on Barton's paper from a New Zealand context, links the discussion of socio-political perspective to the mainstreaming debate in education. Adopting a socio-political perspective changes the focus of discussions of education for children with disabilities from the personal trouble of impairment to the contextual public issues of stigma, power, and discrimination. Comparing the stigmatization of children with disabilities to that of the Maori minority in New Zealand, Ballard calls for a broadened and more diverse discourse that includes the voices of people with disabilities and other oppressed groups.

Gillian Fulcher's paper critically discusses the "economic rationalist" discourse of the Australian welfare state and its corresponding policies and bureaucracy in terms of Barton's socio-political perspective. While agreeing with his call for raising the voices and establishing the rights of people with disabilities, Fulcher cautions that the formal rationality of political rights may not in themselves count for much.

How do these papers enhance an understanding of disability and the ongoing policy and political debates over disability and its role in the contemporary welfare state? Their most important contribution may be to reaffirm the socially constructed and politically disadvantaged status of people with disabilities. While a perspective on disability framed in social and political terms has been analyzed in greater theoretical depth and with broader historical and policy references by others, it is certainly worth restatement and further development in the context of the current policy debates of Britain, Australia, and New Zealand. Although the length and rhetorical format of the papers do not provide very much context on the policy debates at issue, the reader is persuasively convinced that the terms of political discourse are important and that the socio-political perspective is a useful and necessary lens for viewing disability.

An American response to these papers might productively address the U.S. experience of trying to proselytize a socio-political perspective among people with and without disabilities, among service providers, and among policy makers. Laws enacted in the past two decades have not only mandated accessibility and reasonable accommodations, but in many cases have required that people with disabilities play an active role in decisions about services. The most fundamental of these laws is the *Americans with Diabilities Act*, passed in 1990 with strong bipartisan support, despite the generally conservative political and fiscal climate.

These laws have been accompanied by the growth of the disability rights and independent living movements, which have promoted more positive images of people with disabilities among the general public and, perhaps more importantly, among people with disabilities themselves. The values of independence, self-help, and the rejection of handicapping stereotypes have been promoted within a variety of local and national organizations.

The benefits and limitations of changing the terms of political discourse may be particularly evident as the implementation of the *Americans with Disabilities Act* proceeds in the years to come. Over the past quarter century, many Americans with disabilities have redefined their impairments and disadvantaged status in social and political terms and mobilized politically to change public perception and government policy. Over these years, many things have changed. Access to education, transportation, and public

accommodation has dramatically improved. Many architectural and communication barriers have been removed. Clear legal rights have been established, prohibiting discrimination in employment, housing, and public services. These rights and policy achievements are guarded by resourceful and vigilant advocates at the national, state, and local levels. For many people with disabilities, the oppression of stigma and discrimination are less severe as the result of successful political action that redefined disability and the barriers society and government have imposed on people with disabilities.

Nevertheless, Americans with disabilities still face stigma and barriers to full social participation in everyday life and in the programs that serve them. The persistence of massive inequity and inequality is in part a testimony to the difficulty of major social change and the limits of political and policy reform. Inequalities reproduce themselves, even in the face of sincere and well-informed attempts to reverse them. As the authors of these papers suggest, inequalities of class, gender, and ethnicity reinforce those of disability. Further, meaningful cultural and institutional change does not flow easily from changes in political discourse. While changes in political leadership, legal entitlements, and public debate ebb and flow, the inertia of social life, while not inexorable, is formidable. We must also confront the extent to which disabling conditions may impose real limits on social functioning, even if these limits are exacerbated by stigma and discrimination.

The difficulty of change does not mean that struggle should be abandoned, but rather that a long term and incremental strategy may be necessary. Further, while major institutional changes are sought, we cannot afford to neglect smaller changes at the individual, organizational, and community levels. To define disability in political terms and to understand that fundamental change are both difficult and necessary to fully empower people with disabilities should not suggest an exclusive reliance on macrosocietal long term reforms. Rather the mundane discourse of everyday life also must be the focus of efforts to improve the lives of people with disabilities. Individual interactions and community institutions must be redefined in inclusive terms that help to break down the barriers of a disabling society. Such efforts require broad and continual involvement by people with disabilities and their supporters, but they may yield short-term results that enable sustained and widening benefits.

My comments here do not run counter to the papers that are the subject of this monograph; rather they are an attempt to work out the implications of the socio-political perspective for understanding and political action. The authors raise important issues that must continue to be worked out in the variety of contexts in which people with disabilities find themselves. Cross-national and cross-cultural discussions such as this monograph should serve to further such necessary analysis.

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CHAPTER ONE

Disability and the Necessity for a Socio-Political Perspective

Len Barton, Ph.D.

Len Barton is currently Professor and Head of Department of the Division of Education at the University of Sheffield. He is the founder and editor of the International Journal, Disability, Handicap and Society. *His research interests include the politics of Disability, Post-School Opportunities for Disabled People and Disability Research. His latest publication is a co-authored volume with J. Corbett,* A Struggle For Choice: Students with Special Needs in Transition to Adulthood.

This paper attempts to highlight some of the key issues involved in the development and maintenance of a socio-political perspective on disability. It is exploratory and is concerned with encouraging further discussion and dialogue. The approach being advocated is not a popular one in Great Britain yet, but it is increasingly being seen as necessary by numbers of disabled people throughout the world.

Setting the Context

Governments have always been concerned with controlling human service provision. This includes issues of funding, purpose and outcomes. However, what has been markedly different about the past decade in the British context, has been the extent and nature of such interventions. Under the guise of a populist rhetoric of freedom of the individual, consumer choice and the value of competition, an unprecedented series of interventions have taken place. This process covers education, health and welfare provision and has involved the introduction of extensive legislation. Underpinning these developments has been the application of a free market ideology. Government interest has focused on a radical restructuring of provision and there has been a perennial concern with where and how the system is to be managed and what will be the outcome. The emphasis is on control.

Writing on these events in relation to education, Ball (1987) contends that what is going on is conflict over the definition of the schools, what kind of schools they are to be, and struggle over who is to control these definitions, over the focus of the power to define (p. 251).

The sheer number, speed and cumulative effect of these changes in definitions, purposes and priorities, the reformulations of the relationship between the individual and the state, the overthrow of trade union dominance, programs of privatization, the introduction of a new morality reinforcing

conservative values concerning the family and the role of women and the celebration of excessive individualism through a belief in the centrality of the market, all bear testimony to the significant impact of state intervention (Cultural Studies, 1991; Barton, 1991; Hindess, 1990; David, 1986; Dale, 1990; and Whitty, 1989).

In setting the context in which questions relating to disability need to be explored, it is difficult to achieve a satisfactory balance between a recognition of both the power and effectiveness of state control and those real contradictions within and between policies and practices, as well as those unintended consequences that combine to provide the possibilities for contestation and change. For those of us who are committed to the pursuit and realization of a truly democratic society in which issues of social justice and equity are central concerns, then in terms of the prevailing situation, it is crucial that we do not underestimate the difficulties involved. Romantic visions and idealistic rhetoric have too often resulted in human suffering, disappointment and disillusionment.

The actions of Government have not been without critics, and these have covered a range of concerns including the confrontational manner in which Government has conducted itself during this period. Little real consultation has been involved (Simon, 1988); the explicit political interference in, for example, the content of the curriculum and the use of the policy during conflicts with trade unionists (Braid, 1990 and Fine & Millar, 1985); and the deliberate attempts by Government to destroy the role of the local authorities in the administration and control of educational, welfare and housing provision (Ranson, 1990 & Papadakis, 1990).

One of the significant impacts of Thatcherism has been to legitimate the view that education and health, for example, are clearly political issues and that they are high on the Government's agenda. Thus, the nature of schooling, the kind of education children ought to receive, as well as the responsibilities and part teachers play in this process, are all topics of crucial significance in the prevailing climate of public opinion.

This insight is particularly significant when it comes to a consideration of disability. The topic provides an opportunity for raising serious questions about the nature of the existing society and the kind of society we desire. Furthermore, it gives us a concrete example of the complex and contentious nature of discourse and practice. Such discourse is the subject of intense struggles in that participants often adhere to competing objectives and operate from within unequal power relations (Fulcher, 1989). Part of the struggle involves disputes over the meaning of 'disability'. How we approach this activity and the interpretations we construct will be influenced by the values we are committed to. In acknowledging the existence of multiple discourses

and the often antagonistic relationship between them. Ball (1990) maintains:

"Discourses are, therefore, about what can be said, and thought, but also about who can speak, when, where and with what authority. ...Words and propositions will change their meaning according to their use and the positions held by those who use them" (p. 17).

These ideas have their antecedents in the work of Foucault (1977) and are part of a wider interest in the relationship between knowledge and power. In relation to the question of disability, this perspective provides a possibility of highlighting the nature and intensity of the struggles involved over definitions, effective policy and practice. It also offers a way of exploring these relationships between actors in different arenas and levels of the system.

A careful analysis of official and academic discourses surrounding disability uncovers a crucial factor: the absence of the voices of disabled people themselves. Indeed, this is one of the constant criticisms emanating from many of the writings of disabled people. Raising a series of central issues relating to schools, Micheline Mason (1990), a disabled writer, succinctly highlights the realities of this position:

"Where are the studies asking disabled people what they think of their education so far? Where is the consultative mechanism to improve the service according to the needs and aspirations of its consumer? You won't find them. Why not? Because disabled people are still the victims of a deeply held prejudice which essentially says that we are incapable of knowing what is best for us" (p. 303).

This absence of disabled people's voices and concerns is not because they have nothing to say, via the available mediums, but that they are explicitly prevented from speaking. This is related to the ways in which disability is defined and to the expectations and practices associated with such definitions. It is fundamentally about unequal social relations and conditions and the ways in which power is exercised in our society. This both shapes and legitimates the marginalization and exclusion of disabled people. Whose definition is significant, why and with what effects, are questions of importance in this context.

Disability as a Form of Oppression

Disability is a complex issue. Definitions are crucial in that the presuppositions informing them can be the basis of stereotyping and stigmatization. One of the dominant influences shaping policies and practices has been the medical model. From this perspective there is an emphasis upon an individual's inabilities or deficiencies. 'Able-bodiness' is seen as the acceptable criterion of 'normality'. A medical model according to Hahn

(1985) "...imposes a presumption of biological or physiological inferiority upon disabled persons" (p. 89). Terms such as 'cripple' or 'spastic' reinforce such an individualized medical definition in which functional limitations predominate.

Historically, disability has been viewed fundamentally as a personal tragedy, which has resulted in disabled people being seen as objects of pity or in need of charity. They have been subject to discriminatory policies and practices in which the predominant images of passivity and helplessness reinforced their inferior status. One effect of such a perspective is that it provides a variety of individualized responses to disabled people. For example, they are often viewed in heroic terms, as being brave and courageous. Their position is constantly being compared against an assumed notion of 'normality'. Indeed, it is the pursuit of this "which leads to neurosis and is the cause of much guilt and suffering" (Brisenden, 1986, p. 3) on their part.

In the local sports center near my home a picture of a young girl named Vikki is being displayed in the main foyer. Under the heading WEEK AWAY APPEAL, there is the following statement:

"Time is ticking away for this pretty little 8 year old local girl who, without use of her hands or legs, faces a meaningless life in a wheelchair. We can save her from this fate if we can raise £10,000 to send her to the Peto Clinic, Budapest, Hungary. ...If we go to our graves knowing that we have helped Vikki, and hopefully other kids like her to walk and lead purposeful lives, that will do for us. ...We must save these children."

This is a very clear example of disabilist values powerfully influencing the commonsense thinking and language of everyday life, thereby legitimating offensive interpretations. Particular images of disabled people are being reinforced in this example, and they are fundamentally negative.

In a critique of the medical model of disability, Brisenden, himself a disabled person, maintained: "If the experience of disability is always presented in the context of the medical implications it is supposed to have, it will always be seen as largely a matter of a particular set of physical or intellectual dysfunctions and little else" (p. 2).

This homogenized and individualized form of thinking is essentially asocial and depoliticizes questions of definition, expectations and practices.

A Socio-Political Perspective

A socio-political approach provides a very different understanding of

disability and the issues involved. It entails an alternative set of assumptions, priorities and explanations. The analysis is concerned with highlighting the unequal social conditions and relationships within which people interact. It recognizes the centrality of power and the struggles over social justice, equity and rights for disadvantaged groups.

It is an unadaptive, unhelpful environment which needs to be examined and changed. Being interested in disabled people requires an examination of those material conditions and social relations which contribute to their dehumanization and isolation. Writing on the question of the politics of disability, Oliver (1990) a leading disabled analyst, summarizes the essential feature of an alternative position to the medical one. He maintains:

"All disabled people experience disability as social restriction, whether those restrictions occur as a consequence of inaccessibly built environments, questionable notions of intelligence and social competence, the inability of the general public to use sign language, the lack of reading material in braille or hostile public attitudes to people with non-visible disabilities" (p. XIV Introduction). He also argues that disabled people are involved in a difficult struggle in which they must strengthen their endeavors as a political pressure group.

Disability is a social and political category in that it entails practices of regulation and struggles for choice and empowerment (Fulcher, 1989). Thus, for some disabled analysts, merely defining disability as social restriction is inadequate. The issue is not that society ignores disabled people but how it takes them into account. This requires an examination of why society identifies this social group for differential treatment at specific historical moments (Findlay, 1991). It is more than a mere access issue that is on the agenda here. Both ideological and material conditions need to be engaged in the struggle to identify and challenge those discriminatory policies and practices at different levels of the social system.

In a society fundamentally organized and administered by and for white able-bodied males, the position of disabled people in relation to education, work, housing and welfare services is a matter of grave concern (Abberley, 1987; Oliver, 1990). They are compelled to engage in power struggles if they are to achieve equity. This is a scandalous reflection of their marginalization, low-status and vulnerability. Relationships with various professional agencies are often difficult and some disabled people have clearly argued for a range of changes. These include greater choice in the nature and amount of services provided, more control over the allocation of resources, especially in relation to independent living, and new forms of accountability of service providers to disabled people involving clear mechanisms for handling disagreements (Brisenden, 1986; Oliver & Hasler, 1987; Oliver, 1988). In an analysis of social

policy in the past decade Glendinning (1991) discusses these and other issues and seeks to demonstrate that matters have actually worsened and:

"The economic and social policies of the last decade have done little to enhance, and much to damage, the quality of life of disabled people. Despite the rhetoric of 'protecting' the most 'deserving', 'vulnerable', or 'needy', much of this 'protection' has been illusory" (p. 16).

Such events have resulted in a serious reduction in the degree of autonomy and choice of disabled people but an increase and intensification of "scrutiny and control by professionals and others"(p. 16). These forms of handicapping conditions and relations encourage passivity and dependency on the part of disabled people (Bishop, 1987). It is integral to the process of learned helplessness in which problems are depicted as personal troubles rather than public issues (Mills, 1970).

So far I have argued that disability needs to be understood as a form of oppression. Being disabled entails social and economic hardships as well as assaults upon self-identity and emotional well being. However, it would be both disabilist and misleading to give the impression that disabled people are a homogeneous group. Terms such as 'the disabled' are a catch-all and give an impression of sameness. However, the difficulties and responses to being disabled are influenced by class, race, gender and age factors. These can cushion or compound the experience of discrimination and oppression. For example, in a study of disabled women receiving care, Begum (1990), a disabled black woman, maintains:

"... women with disabilities are perennial outsiders; their oppression and exclusion renders them one of the most powerless groups in society. The personal care situation encapsulates so many different dynamics that for many women with disabilities it becomes the arena where their oppression becomes so clearly magnified and distilled" (p. 79).

Supporting this perspective, Morris (1989) illustrates from the lives of a group of disabled women, including her own, that matters of privacy, body-image and sexuality are a source of tension and difficulties in relation to the 'care' situation. Also, she highlights the disadvantages disabled mothers experience in having responsibility for the upbringing of the children, general running of the home, as well as maintaining some form of outside employment. The degree to which individuals can survive within these conditions will be largely contingent upon their socio-economic circumstances. The more they can afford, the greater the chances of coping. Unfortunately, few disabled people are in well-paid employment and therefore the overall situation is very bleak indeed. Borsay (1986) contends that many disabled people are located at the bottom of the income ladder, or out of work and

dependent upon social security benefits (p. 184).

Given that the political discourse is now largely one of the market and that any policies have tended to bunch up in an ad hoc fashion without a coherent framework to guide policy development (Borsay, p. 183), inequalities of provision and opportunity are being exacerbated. Questions of social justice and equality have become marginalized within this type of socio-economic climate. In the struggle for empowerment, disabled people and able bodied colleagues must strive to move the overriding interest in questions of needs to those of rights and choices (Hudson, 1988). Critical attention can thus be given to those structural and institutional factors which constrain and serve the interests of the more powerful (Oliver, 1989). Oppression is more than a denial of access and opportunity, it is about being powerless and viewed as essentially worthless in an alien society. This is what disabled people struggle against in their efforts to learn self pride and dignity (Findlay, 1991).

Being disabled does not mean that there is an automatic understanding and acceptance of other disabled people. This is part of a learning process leading to a collective identity. Some disabled gay and lesbian people feel isolated from their disabled colleagues and not adequately represented in the organizations of disabled people. Not all disabled people are political in the way in which disabled authors referred to in this paper are. Some are willing to work within the system and seek the changes that way. Much work remains to be undertaken in order for the struggle to be based on an agreed set of values and agendas.

(Editors note: In the U.S., I doubt whether there could, would, or should ever be an "agreed upon set of values and agendas." There is strength in diversity, isn't there? However, the "diversity" of ideas, positions, values and viewpoints that stimulate growth and change did manage to produce The Americans with Disabilities Act *(ADA) which is truly landmark legislation.)*

Equal Opportunities

Political action is required if disabled people are to exercise control over their lives and set their own agendas in relation to full participation in society. This is both a serious and urgent task. It is one which disabled people through their organizations are increasingly taking on board. Writing on the question of the implementation of 'Local Authorities Equal Opportunities Policies', Leach (1989) captures these sentiments in the following contention:

"Disabled people's issues are still seen, across much of the political spectrum, as largely non-political. Paternalism and the exclusion of disabled people from participation in decision making, is still largely the norm" (p. 75).

Given the nature of the definition of disability that this paper has been concerned to briefly outline, it is essential that this issue is seen as an integral part of an equal opportunities perspective. This is for several reasons. First, because the experience of disability is part of the wider and fundamental issue of prejudice and economic inequality in which ideologies perform a socially divisive role. Such a framework will provide a stimulus for the crucial task of establishing connections between other discriminating groups in order that some common struggles can be engendered. Secondly, it will offer a basis for the identification of those features of the existing society, policy and practice that are unacceptable, offensive and need to be challenged and changed. Thirdly, it will be a means of critiquing individualized and deficit models and interpretations. It removes the emphasis from one of being depicted as a personal trouble to that of a public issue. Finally, it will contribute to such policies being non-disabilist by redressing the extent to which disability has been excluded from them, or merely attached as a tokenistic gesture (Leach, 1989 and Rieser & Mason, 1990).

In presenting this type of perspective it is important to be aware of how 'equal opportunities' can mean different things to different people. It is not about gaining access or being able to compete against able-bodied people on equal terms. The stakes are much higher than this. What is required is a direct challenge to the status quo. The struggle for equal opportunities is one of disabled people being able to set their own agendas, define their needs and have real choices and rights. Thus as Findlay (1991), a disabled person, also argues:

> "Equal opportunities, therefore, means a struggle by people with disabilities to set a political and social agenda. We must demand that the idea of 'disability' as a 'welfare issue' is scrapped. The power structures as well as the material structures which disadvantage and marginalize us, must both be up for discussion. It is not just an issue of having more choice in what is provided for us, but it is also about having the chance to control aspects of the services too" (p. 14).

The breaking down of structures and their ideological supports which exclude, debilitate and control disabled people, must be part of a process which seeks some ultimate liberation and empowerment. In relation to integration, Branson and Miller (1989) maintain this means that "integration must be a policy, a program, oriented towards its own destruction" (p. 161). This involves the abolition of the categories which both conceptually and actually exclude or devalue oppressed groups.

Various analysts have also challenged the limited version of some interpretations of equal opportunity. This is particularly in relation to its ineffectiveness to provide alternative values and concepts of socialist education (Lauder, 1988). Others have criticized the ways in which some reforms

in the name of equality of opportunity have been a means by which the state has prevented more radical, revolutionary changes (Hall, 1988). Feminists have highlighted weaknesses in the theoretical bases of equal opportunities approaches. These include simplistic notions of learning, gender identity formation and stereotyping. Too often the outcome has been an emphasis on individual change rather than the structures which oppress them. This type of focus justified operating within existing structures as opposed to seeking their removal (Arnot, 1991). Given these limitations, the argument for disability being an integral component of equal opportunities needs to both recognize and struggle against any crude reformism, unwitting complicity, or the softening of the endeavors that will be required if the empowerment of disabled people is to be real and effective. On this basis the demand for equal opportunities is a transitional one (Findlay, 1991).

A politics of disability can draw some lessons from feminist thought and practice. For example, connecting the personal with the political so that what has been depicted in mainly individual terms can be viewed as a social predicament. Making their standpoints known to both themselves and to others is a central part of the agenda (Eisenstein, 1984). This can be a means of developing a stronger individual and collective sense of worth and effort.

A Necessary Approach

In this paper I have briefly maintained that disability must be viewed as a form of oppression. On the basis of this, the necessity for a socio-political perspective can be identified and defended. It is necessary because it is the only approach which offers a way of adequately engaging with the complex and contradictory issues involved. The centrality of social conditions and relations which entail both ideological and material factors are key aspects of this perspective. Disability is thus to be understood as part of a wider set of inequalities and social formations. This approach is also necessary because it provides a basis for disabled people to develop a sense of human dignity and identity. Furthermore, it confirms the view that disability is a political issue and thus entails, seriously examining consumer rights and raising questions about whose interests do particular provisions serve and who benefits from them. It also powerfully reminds us, that current ideologies and practices are neither natural nor proper. They are a social creation and as such can be subject to change.

This perspective is also necessary in that the position of the state government is given particular attention, and importantly, the political will required for the development and implementation of appropriate legislation and support. Finally, this way of understanding and explaining disability provides a much needed antidote to those forms of discourse which encourage the pursuit of slick and easy answers, to what are complex and

contentious issues.

Conclusion

In Great Britain, we have no room for complacency. Presently we have a *Race Relations Act* and a *Sex Discrimination Act*, but no anti-discrimination legislation in which the rights of disabled people are enshrined. Several disability groups are currently protesting against the Government's decision to scrap vital sections of the 1986 *Disabled Persons' Act*. Failure to implement these sections will inevitably have very serious effects on both Advocacy and Rights entitlements (*Disability Now*, 1991).

Disabled people are increasingly becoming politicized and outspoken in their demands for fundamental changes. In the struggle for change greater support is being given to the development of a disability movement. This has both practical and political aspects. The future developments are not without their difficulties as Oliver (1990) notes in a discussion of the movement and its relationship to the state:

> "... the disability movement has to decide how it wishes such a relationship to develop. Should it settle for incorporation into state activities with the prospect of piecemeal gains in social policy and legislation with the risks that representations to political institutions will be ignored or manipulated? Or should it remain separate from the state and concentrate on consciousness-raising activities leading to long-term change in policy and practice and the empowerment of disabled people, with the attendant risks that the movement may be marginalized or isolated" (p. 128).

The stakes are high. The issues are profoundly serious. The situation demands urgent attention. In order for disabled people to participate in the construction of agendas and exercising of choices in relation to their lives, the struggle for change will entail rights, power and control being central to the emancipatory process.

Finally, when Martin Luther King, the American civil rights leader, made his famous speech in which he said with regard to the United States:

"I have a dream that one day this nation will raise up and live out the true meaning of its creed - we hold these truths to be self evident that all men (sic) are created equal."

He uttered these words in the face of a racist society which had a history of slavery and discriminatory policies and practices. He spoke from personal knowledge of the effects of such an oppressive system. He dreamed, he hoped, he had a vision. He paid the ultimate price for his beliefs.

Our problem as professionals and able-bodied people is that we do not

recognize that disabled people dream. We urgently need to acknowledge, listen to and act upon their hopes and views.

Amidst all the distractions of professional discourse and empty rhetoric, the voices of disabled people need to be heard. Part of this struggle involves the development and maintenance of a socio-political perspective of disability.

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References

Abberley, P. (1987). 'The Concept Oppression and the Social Theory of Disability' in *Disability, Handicap and Society*, Vol. 2, No. 1, pp. 5-19.

Arnot, M. (1991). 'Democracy, Equality and Social Justice' in *British Journal of Sociology of Education*, Vol. 13, No. 4, (Special Issue on Democracy).

Ball, S. (1990). *Politics as Policy Making in Education and Explorations in Policy Sociology*. London: Routledge.

Ball, S. (1987). *The Micro-Politics of School Life*. London: Methuen.

Barton, L. (1991). 'Teachers under Siege: A case of unmet needs' in *Support for Learning*, Vol. 6, No. 1, pp. 3-8.

Begum, N. (1990). 'Burden of Gratitude: Women with Disabilities Needing Personal Care' in *Social Care: Perspectives and Practice Critical Studies*. Warwick: University of Warwick.

Bishop, M. (1987). 'Disabling the Able?' in *British Journal of Special Education*, Vol. 14, No. 3, p. 98.

Borsay, A. (1986). 'Personal Trouble or Public Issue? Towards a model of policy for people with physical and mental disabilities' in *Disability, Handicap and Society*, Vol. 1, No. 2, pp. 179-196.

Braid, M. (1990). 'Determined to Make History a Matter of Fact' in *Independent*, Education Section 5.4.90, p. 23.

Branson, J. and Miller, D. (1989). 'Beyond Integration Policy - The Deconstruction of Disability' in Barton, L. (ed.) *Integration: Myth or Reality?* Lewes: Falmer Press.

Brisenden, S. (1986). 'Independent Living and the Medical Model of

Disability' in *Disability, Handicap and Society*, Vol. 1, No. 2, pp. 173-178.

Cultural Studies (1991). *Education Limited: Schooling and Training and the New Right Since 1970*. London: Unwin Hyman Ltd.

Dale, R. (1990). *The State and Education Policy*. Milton Keynes: Open University Press.

David, M. (1986). 'Teaching Family Matters' in *British Journal of Sociology of Education*, Vol. 7, No. 1, pp. 35-58.

Disability Now (1991). 'National Protest over loss of advocacy rights' in *Disability Now*, June, pp. 1 & 3.

Eisenstein, H. (1984). *Contemporary Feminist Thought*. London: Unwin Paperback.

Findlay, B. (1991). 'Disability, Empowerment and Equal Opportunities' (Unpublished paper).

Fine, B. and Millar, R. (eds.) (1985). *Policing the Miners' Strike*. London: Lawrence & Wishart.

Foucault, M. (1977). *The Archaeology of Knowledge*. London: Tavistock.

Fulcher, G. (1989). *Disabling Policies: A Comparative Approach to Education Policy and Disability*. Lewes: Falmer Press.

Glendinning, C. (1991). 'Losing Ground: Social Policy and Disabled People in Great Britain, 1980 - 90' in *Disability, Handicap and Society*, Vol. 6, No. 1, pp. 3-20.

Hahn, H. (1985). 'Towards a Politics of Disability' in *Social Science Journal*, Vol. 22, Part 4, pp. 87-105.

Hall, S. (1988). *The Road to Renewal*. London: Verso.

Hindess, B. (ed.) (1990). *Reactions to the Right*. London: Routledge.

Hudson, B. (1988). 'Do People With a Mental Handicap Have Rights?' in *Disability, Handicap and Society*, Vol. 3, No. 3, pp. 227-238.

Lauder, H. (1988). 'Traditions of Socialism and Educational Policy' in Lauder, H. & Brown, P. (eds) *Education in Search of a Future*. Lewes: Falmer Press.

Leach, B. (1989). 'Disabled People and the Implementation of Local Authorities' Equal Opportunities Policies' in *Public Administration*, Vol. 67, No. 1, pp. 65-77.

Mason, M. (1990). 'Disability Equality in the Classroom - A Human Rights Issue' in *Gender and Education*, Vol. 2, No. 3, pp. 363-366.

Mills, C.W. (1970). *The Sociological Imagination*. Harmondsworth: Penguin.

Morris, J. (ed.) (1989). *Able Lives: Women's Experience of Paralysis*. London: The Women's Press.

Oliver, M. (1990). *The Politics of Disablement*. London: Macmillan.

Oliver, M. (1989). 'Disability and Dependency: A Creation of Industrial Societies' in Barton, L. (ed.) *Disability and Dependency*. Lewes: Falmer Press.

Oliver, M. (1988). 'The Political Context of Educational Decision Making: The Case of Special Needs' in Barton, L. (ed.) *The Politics of Special Educational Needs*. Lewes: Falmer Press.

Oliver, M. & Hasler, F. (1987). 'Disability and Self-Help: A Case Study of the Spinal Injuries Association' in *Disability, Handicap and Society*, Vol. 2, No. 2, pp. 113-125.

Papadakis, E. (1990). 'Privatization and the Welfare State' in Hindess, B. (ed.) *Reactions to the Right*. London: Routledge.

Ranson, S. (1990). *The Politics of Reorganizing Schools*. London: Unwin Hyman.

Rieser, R. & Mason, M. (eds.) (1990). *Disability Equality in the Classroom: A Human Rights Issue*. London: ILEA.

Simon, B. (1988). *Bending the Rules: The Baker 'Reform' of Education*. London: Lawrence & Wishart.

Whitty, G. (1989). 'The New Right and the National Curriculum' in *Journal of Education Policy*, Vol. 4, No. 4, pp. 329-341.

CHAPTER TWO

A Socio-Political Perspective on Disability: A Comment from the New Zealand Context

Keith Ballard

Keith Ballard has professional training and experience as a teacher and educational psychologist and is currently Associate Professor in Education at the University of Otago, New Zealand. His present research program includes work on reflective practice with teachers in an inclusive school and work with parents of children with disabilities in an action research project focusing on policy and practice in education health and welfare services. His publications are in the areas of assessment and child development and learning, teaching children and adults who have intellectual disabilities and mainstreaming policy and practice.

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Barton sees disability as "a social and political category" that results in people with disabilities experiencing "powerlessness and worthlessness in an alien society" organized predominantly "by and for able-bodied males....." Disability is, therefore, "part of a wider set of inequalities and social formations", all of which result in oppression. Nevertheless, because oppressive ideologies and practices are "social creations" rather than inevitable outcomes of impairment, they are "subject to change", particularly through political action opposing discrimination and supporting civil rights.

Barton's emphasis on the *complexity* of disability issues is consistent with other critical perspectives on the models and concepts that most frequently guide research and action in assessment (Biklen 1988), education (Skrtic 1986), health (Salzinger, Antrobus & Glick 1980), and family services (Bronfenbrenner 1979, 1988). These critiques also identify the need to address the social and political context of disability. The present comment on Barton's paper derives from an ecological perspective on disability issues in education in New Zealand (Ballard 1990, 1991). This approach interprets child and family experiences in the context of prevailing beliefs and ideologies regarding disability. In identifying oppressive policies and practices it lends support to the primacy of socio-political factors for both research and advocacy agendas on disability.

The political context: reforming the state

The election to government in 1984 of what had traditionally been a Left Wing (Labor) political party resulted in a "New Right revolution in New Zealand which has sought to change the relationships between the state, the economy and civil society" (Lauder, 1990, p. 1). Policies driven by this

ideology have been vigorously pursued by subsequent governments, with education having a particular focus.

The report that led to the initial restructuring of educational administration has been described as "a characteristic document of the New Right" (Nash, 1989, p. 121) stressing individualism and reflecting the notion that education is not a "public good" but a "commodity to be traded in the marketplace" (Grace, 1988, p. 14). Education 'providers' (i.e. schools), therefore, must be independent, self-managing and competitive. Following the election in 1990 of a Right Wing (Conservative) government, reforms have focused on the curriculum as a tool of economic development, and on the examination system as a mechanism for improving teacher accountability and student achievement. The development of a "National Curriculum" has begun without mention of disability and has been discussed in terms similar to those of the "excellence in education" movements in America and Britain (e.g. Altbach, 1985) which argue that emphasizing equality of opportunity in schools has contributed to a lowering of educational standards.

Under the Labor government (1984-1991) there was recognition that reducing the role of the state in education could disadvantage those who, for reasons of socio-economic background, gender, disability or minority ethnic group, might not have an equal voice in schools that were 'self-managed' by parent Boards of Trustees. The Labor government, therefore, required that statements supporting equity be written into each 'School Charter', the mechanism through which schools contract with their local community and the new Ministry of Education to meet stated goals. Also, additional 'equity' funding was to be made available to schools according to the socio-economic, ethnic, disability and other 'special needs' components of the school's community.

The current government, however, has reduced equity goals to 'voluntary' status and there are uncertainties over funding. In addition to presenting problems in the disability area, this change in policy may have particular significance for the indigenous Maori people who comprise a youthful 15 per cent of New Zealand's 3.3 million population, and whose educational and economic needs have not been well served since European settlement.

Education politics

Until recently, New Zealand has managed disability in its schools by evolving a 'dual' special-regular education system similar to that of Britain and America. There has, however, long been pressure from parents and disability groups advocating the right of all children, irrespective of ability or disability, to inclusion in the state school system. The most significant outcome of this integration movement has been legislation enacted in 1989 that gave the right

to every student to "free enrollment and free education at any state school" (Ballard 1990). To date, the power of the legislation has not been fully tested. This means that in some communities there are schools that readily integrate all students, while in others parents confront resistance to inclusion. Such resistance is supported by the present Minister of Education, who believes that mainstreaming should only be undertaken where "resources can be provided" and that for persons with severe disabilities "the cost (is) too high", so that integration for them should not be pursued (Smith 1990). Economics, therefore, sanctions discrimination against students with disabilities.

It is unusual to see segregation justified in terms that so clearly devalue disabled students. Separate special education in New Zealand is most often supported from a discourse (Fulcher 1989) on the "best interests of the child", determined by professionals on the basis of assessment strategies that are claimed to be objective and scientific. As Skrtic (1986), among others (e.g. Biklen 1988), has shown, this approach uses biological concepts from pathological medicine and statistical concepts of deviance from psychology to conceptualize disability as a 'condition' of individuals.

Socio-Political models, on the other hand, identify disability as a creation of specific social and historical contexts. For example, through the 1970s in New Zealand, children and young people who had Down Syndrome were identified in official policies and practices as being 'uneducable'. They were, therefore, largely excluded from ordinary schools. Now, however, they successfully participate in ordinary age-appropriate settings from preschool to high school (Ballard 1991). It is clearly not the children, but our ideas about them, that have changed.

Parents have long recognized that identifying disability as a 'personal trouble' is how the education system denies its responsibility for their child. As Colleen Brown (1990) has said, "a cringe phrase (from professionals) for parents is 'in the best interests of the child'. Surely the parents know this. Who questions us with our other children?" Nevertheless, the power remains largely with the professional, with the result that the list (of systems problems) seems endless to the embattled parent.

New tactics and strategies have to be thought up to counter the moves made by the opposition. It is a contest, often exhausting to the parent, tiresome and petty. Parents have had to organize themselves into support groups because what the public has had to realize is that we are survivors and what is more we are the only people who are going to actively seek justice for our children (Brown, 1990, p. 26).

Such parents do not see their children in terms of psycho-educational categories, but in terms of young people who are actively discriminated

against. Colleen Brown goes on to say:

"Continually parents ask themselves: 'Why should I have to do this?' What makes this child so different from others in the community? If parents had to 'sell' each of their children to the education system, what a hue and cry there would be. Yet it is expected of parents of children with special needs. ...The message is you are not of equal value to me and you are a problem" (p. 26).

Cultural politics

The language of struggle is also evident in the voice of Maori whose educational (and therefore socio-economic) needs have been poorly served by an education system that has largely excluded their language and culture. Kaai-Oldman (1988) has described how Maori parents have now moved to "obtain control and power over the decision-making processes affecting their children's lives" by establishing Maori language preschools and schools(p.27). She notes that "the unforeseen side effects" of these educational efforts involve many young parents "becoming politically active as they grapple with constraints imposed by Pakeha (European) bureaucracy for an equitable distribution of those resources required to attain their goals" (p. 27).

In a study of Maori perspectives on intellectual disability (Bevan-Brown, 1989), a mother described how her five-year-old son was hospitalized for assessment. She remembered the professionals saying that her son should be institutionalized because "he'd never be able to do anything . . . they were adamant" (p. 76). The parents had rejected the prognosis and recommendation. When the researcher asked if anyone else disagreed with the professionals, the mother replied:

"Yes, the domestic staff did. They worked around his bed and that and they said R. talked to them, pointed to anything he wanted if they couldn't understand him or that sort of thing.... They said 'Hey listen Mrs. R., he'll do anything, he can communicate and that's all that matters.'"

(The researcher asked if the domestic staff were Maori or Pakeha.)

"Maoris, Maoris they'll talk to anybody and they'll get people talking to them. They used to clean around him, talk to him . . . (but) as soon as he saw the doctors coming, Brmm, he'd just close up completely . . . that's what they told us" (pp. 76-77).

A socio-political perspective (including the historical antecedents to present Maori-European relationships) seems essential for interpreting this mother's story. What was predicted to happen to this child and the basis for

those predictions can best be understood in terms of the cultural and status (power) differences among the participants which influenced what they experienced and how they interpreted those experiences. These contextual factors differentially determined the meaning of the child's physical and intellectual impairments to the parent, domestic staff and professionals.

Research politics

Ecological research models identify the importance of overriding belief systems, values and ideologies that give "continuities of form and content" to society's political and related actions (Bronfenbrenner, 1979, p. 258). As Glossop (1988) suggests, the ecological paradigm represents a move away from the idea that we might build pictures of human development by aggregating research that is "reductionist" and "fragmented" (p. 4), toward the idea "that it is the context that determines the content"–that is, the context is "responsible for the characteristics displayed by any analytically distinguished 'part'" (p. 8), which would include, in Barton's terms, "the interpretations we construct on the meaning of disability" (p. 5).

The complexity of interrelated systems makes ecological research "messy, time consuming and expensive", (Salzinger, Antrobus & Glick, 1980, p. xvii), but its importance lies in its inclusion of a socio-political perspective and in two further respects. First, it highlights phenomenological data, valuing, as Barton suggests, "the voices" of participants in the research process. Second, it requires of the researcher (and of other professionals) that they identify *themselves* as part of the ecology of disability. They should, therefore, undertake an ongoing critical analysis of their concepts, statements and written work to identify liberating and oppressive positions on disability. Taylor (1988), for example, shows how the concept of the "least restrictive environment" ensures that some people will be restricted; Biklen (1988) suggests that the 'clinical' models used by education and health professionals assign people with disabilities to a 'patient' status which prevents them being seen as a minority group who face "social ostracism and discrimination"(p. 128); while the disproportionate assignment to separate special education of Maori in New Zealand (Bevan-Brown, 1989) and of other minority students and those living in poverty elsewhere, involves a social bias that challenges the credibility of the categorical assessment strategies used to separate the 'disabled' from mainstream educational opportunities.

While researchers debate the significance of a socio-political perspective, disabled people, parents struggling to achieve integration through mainstreaming, oppressed indigenous people and other ethnic minorities have increasingly identified the salient role of power and politics in their lives. Being aware of these issues, researchers could direct resources they control toward understanding and liberation, perhaps through empowerment and

partnership in action research. Acknowledging the need for a socio-political perspective may, however, be only an initial step. The analytical tools needed to reveal and understand social contexts, their meanings and effects, may require an interaction of areas such as sociological, ecological, ethnographic and discourse analysis, together with some risk taking in crossing interdisciplinary boundaries.

There is also a pressing need to support research from indigenous cultural perspectives. This would contribute to a metatheoretical critique (Skrtic, 1986), extending our world views beyond those currently maintained within dominant paradigm and cultural perspectives. While the voice of those with disabilities identifies the socio-political imperative, researchers may also have to listen to one another in order to learn how to respond usefully to that demand.

References

Altbach, P. G. (1985). 'The great education "crisis"'. In P. Altbach, G. Kelly, & L. Weis (eds.), *Excellence in Education: Perspectives on Policy and Practice* (pp. 13-27). New York: Prometheus Books.

Ballard, K. D. (1990)."Special Education in New Zealand: disability, politics and empowerment'. *International Journal of Disability, Development and Education*, 37, pp. 109-124.

Ballard, K. D. (1991). 'An ecological analysis of progress toward non-restrictive environments in New Zealand.' In A. Ashman (ed.), *Current themes in integration: The Exceptional Child Monograph No. 2*, pp. 23-35. Brisbane: Fred and Eleanor Schonell Special Education Research Centre.

Bevan-Brown, J. (1989). *Intellectual Disability: A Maori Perspective*. M.Ed. Research Study, Massey University, Palmerston North.

Biklen, D. (1988). The myth of clinical judgment. *Journal of Social Issues, 44(1)*, pp. 127-140.

Bronfenbrenner, U. (1979). *The Ecology of Human Development: Experiments by Nature and Design*. Cambridge, MA: Harvard University Press.

Bronfenbrenner, U. (1988). Foreword. In A. R. Pence (ed.), *Ecological Research with Children and Families: From Concepts to Methodology (pp. ix-xix)*. New York: Teachers College Press.

Brown, C. (1990). 'Fight for children left for the crows.' *Dominion Sunday Times*, April 26, p. 29.

Fulcher, G. (1989). *Disabling Policies? A Comparative Approach to Education Policy and Disability*. London: The Falmer Press.

Glossop, R. G. (1988). 'Bronfenbrenner's ecology of human development: A reappreciation.' In A. R. Pence (ed.), *Ecological Research with Children and Families: From Concepts to Methodology* (pp. 1-15). New York: Teachers College Press.

Grace, G. (1988). *Education: Commodity or Public Good?* Wellington: Victoria University Press.

Lauder, H. (1990). 'The New Right revolution and education in New Zealand.' In S. Middleton, J. Codd & A. Jones (eds.), *New Zealand Education Policy Today: Critical Perspectives* pp. 22-29. Wellington: Allen & Unwin Port Nicholson Press.

Kaai-Olman, T. (1988). 'A history of New Zealand education from a Maori perspective.' In W. Hirsch & R. Scott (eds.), *Getting it Right: Aspects of Ethnicity and Equity in New Zealand Education* (pp. 22-29. Auckland: Office of the Race Relations Conciliator.

Nash, R. (1989). 'Tomorrow's schools: State power and parent participation.' *New Zealand Journal of Educational Studies, 24*, pp. 113-138.

Salzinger, S., Antrobus, J., & Glick, J. (eds.) (1980). *The Ecosystem of the "Sick" Child: Implications for Classification and Intervention for Disturbed and Mentally Retarded Children*. New York: Academic Press.

Skrtic, T. M. (1986). 'The crisis in special education knowledge: A perspective on perspective.' *Focus on Exceptional Children, 18*(7), pp. 1-16.

Smith, L. (1990). Reported in *Otago Daily Times*, 21 April.

Taylor, S. J. (1988). 'Caught in the continuum: A critical analysis of the principle of the least restrictive environment.' *Journal of the Association for Persons with Severe Handicaps, 13*(1), pp. 41-53.

CHAPTER THREE

Pigs' Tails & Peer Workers

Gillian Fulcher

Gillian Fulcher has taught sociology at Monash University, Australia, and was main writer policy analyst for the Ministerial Review of Educational Services for the disabled for their report, Integration in Victorian Education. She has published widely on policy. Her book, Disabling Policies? A comparative approach to education policy and disability, *was published in 1989 by Falmer Press. She is currently researching a project on education and social justice at La Trobe University, Victoria, Australia.*

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In a large country town, where official statistics record some eleven per cent[1] *(see page 28 for all endnotes)* of the town's inhabitants as unemployed, a young woman ends three weeks of work. She is called a 'support worker' and in this time she has taught herself how to do the job which, on Monday, she will start to teach someone else to do. She sheds her overalls and showers three times. Her children say they can still smell her work: all day, she has been cutting off pigs' tails. The person she will start to train on Monday has an intellectual disability.

In metropolitan Melbourne, where over 3 million of the State's 4.3 million live[2], two professionals, one a worker in welfare, the other a researcher, meet with six people with sight loss, some paramedical clinic staff and two optometrists. The setting is a clinic in a professionalized, once charity-based agency, where patriarchy presides: senior managers, regional and central, are men. The agency has nursing homes, Day Activity Centers for 'the blind' and, in 1991, this new, not-a volunteer and not-a-quasi-professional, peer worker service. The peer workers are enormously enthusiastic. The group who meet –all women except two of those with sight loss–is to discuss the first months of this new work. Once the chief co-ordinator leaves, the meeting opens up. All the talk is positive, but perhaps the most telling comes from an optometrist: "Peer workers have changed the process completely; by the time [newcomers to the clinic] get to us, they've spoken with a peer worker and we can get on with the technical issues."

As the group's scribe, the researcher's task will be to write this meeting up for a third report to the senior men. In the following weeks the peers work on; the welfare worker is moved out of the clinic but is allowed to set up the same kind of groups as those which preceded this project; the researcher's employment, along with that of several others, is 'terminated' due to financial cuts; but the report was in.

In Canberra, Australia's capital, where Federal politicians and most of

the Commonwealth's public servants and bureaucracies reside - though some of their colleagues work in State capitals and, less frequently in other areas - a senior bureaucrat considers the recommendations of a Melbourne-based but Commonwealth-employed bureaucrat. The recommendations concern funding for a group home for people with disabilities[4]. None of the group's proposed members can speak in terms the project worker can understand. The public servant is not sure these people have exercised their right of 'choice' as to where they should live: he decides to check with his Melbourne colleague. The Melbourne colleague checks with his project worker: she decides to confirm that choice has been exercised. Confirmation goes to Canberra.

The background to these events is the rapidly restructuring Australian welfare state. Is there a political unity behind pigs' tails, peer workers and mute choice? Is there a socio-political perspective which has something useful to say about disability, rights and voice?

The broader context

Since 1985, and the *Handicapped Programs Review*, disability has become increasingly important in shifts in the welfare state. Voice, understood as participation and consultation, 'rights' and 'enabling' legislation, have been central for both Federal and Victorian State governments. Equally influential has been what Hindess (1991:a) describes as a central idea in what we call western democracies: the general idea of a political community of autonomous individuals who can be governed by means that depend on their rational consent. Both Federal and Victorian labor government have made much of consensus decision-making and of the ideas of consultation and participation therein. What are the outcomes of these ideas and in what institutional conditions have they been inserted?

Legislation as protection?

The *Disability Services Act* 1986 (DSA) (C), the *Intellectually Disabled Persons' Services Act 1986* (IDPSA) (V) and the *Equal Opportunity Act* 1984 (EO) (V) might be seen as models of protection (themes of rights, dignity, choice, independence, outcomes, and assessment appear unevenly), except that intellectual disability services in Victoria are of great concern (Victoria Advocacy League for Individuals with Disability (VALID) August 91; Victorian council of Social Services (VCOSS), 1991; ABC TV 25.9.91), the EO Act contains exemption clauses[5] and the case taken by nine complainants to the EO Board, in late 1989, by the Disability Resource Center (DRC), that changes proposed to the public transport system would illegally discriminate against people with disabilities, some 20 months later, is lost in the legal process.[6] How do disability groups respond to legislative conditions?

Disability groups position themselves differently, and shift. "If we lose (the claim at the EO Board), we would have to question how effective the Board really is in protecting people's rights" (*DEAC News*, March 1990).

A group opposing DRC's position in 1989, and committed to co-operative working with government, says the farce continues.' In the Victorian consultations (September 1991) disability groups welcomed the proposed national legislation to prohibit discrimination on the grounds of disability: a 'start' said a high profile supporter of Waters vs. the Transport Corporation. The Disability Employment Action Center sees the Social Security (Disability and Sickness Support) Amendment Bill 1991, as 'a major shift...from a position where people with disabilities are considered incapable of work, to one which says...we should and must work', which has 'punitive' features: 'move to where suitable work theoretically exists in Australia... work for under-award wages, if DSS' thinks this is reasonable...apply for or do work that DSS thinks is suitable' (*DEAC News*, August 91:4).

Economic rationalism

In numerous arenas where government consults, economic rationalism is the dominant discourse. Writing from a political perspective on the state, Pusey (1991:202) suggests "The economic rationalists are the leaders [in the public service in Canberra] because they have done the best job on 'capitalizing' on the relativism of modernity." With its themes of productivity and cost, effectiveness and efficiency, accountability and consumer outcomes, economic rationalism presents an illusion of achievement in an era of uncertainty. Its technology of rationality, (Ball, 1990:157) e.g. the allocation of resources with equity, offers to solve apparently intransigent problems.

In these arenas, people grapple with the terms and tenets of economic rationalism. *Parent Voice* (1991) drafts a policy to ask government for 'absolutely equal resource allocation' between children, while the Aging Parents Group makes claims of social justice: 'because we have saved this government thousands of dollars.' Middle-level bureaucrats sit bemused in an evaluation research meeting', tangling with concepts of performance indicators even for such a relatively measurable program as Meals on Wheels'. An executive director is heard to ask: "What are our performance indicators?" Thus, the discourse captures even those who deploy it on others (Ball, 1990:156, citing Foucault)

Against this 'imperialistic discourse' (Ball 1990:157), earlier themes are reworked': social justice becomes money due, dependency becomes How much time will you take? What will it cost to help Mr. A. find his clothes, his way to the dining room and his food on his plate? Well, more than it will to leave Mrs. B., demeaning and immobile, in her bed. Managers whose minds

are on money matters, struggle to shift their everyday concepts (How can Mrs. B. be 'less dependent'?). In a move the legislation (DSA 1986) allows (the Minister may formulate guidelines) rights shift to 'user rights.' Were they ever those of citizen's in a laborist, selective, male wage-earner's welfare state?

It is here, with its empirical-rationalist epistemology, its promise that we can capture a rational world, that the mania to measure derives: the politics of measures masked. In disability policy this includes CAM (Care Aggregated Module), SAM (Standard Aggregate Module) and the RCI (Resident Classification Index): these are measured by DONs (Directors of Nursing), sometimes by GAT (Geriatric Assessment Teams). In various arenas (Integration Support Groups in schools), as in Britain, those thought to be disabled are increasingly scrutinized and oppressed by these measures. In agencies, managers subject employees to internal performance appraisal, while consumers (and their?) outcomes are measured or fudged for the sake of 'accountability'. Reports (Klugman, 1991; Pathfinders, 1990) suggest government measure people with disabilities for Skillshare[10] and work; 'even if only one percent of these people enter employment, this would be a substantial saving to government; international consultants report to 'peak' organizations (traditional disability agencies) in struggles for money from Community Services Victoria. In these ways, by these measures, money is handed to a nursing home, or received in taxes paid by someone newly in work.

Which socio-political perspective?

Which socio-political perspective can make sense of pigs' tails, peer workers, and these other practices? Each is an outcome of limited struggles in a broader context where legislative and other institutional conditions can be deployed or present constraints for different objectives.[11] Both the *Social Security Amendment Bill* 1991, and the DSA 1986, can be used to justify pigs' tails, while the 1986 Act was deployed as a tactic to legitimate the project on peer workers. In this limited project, in unlikely circumstances, this and other tactics achieved a limited objective. This perspective requires political calculation in each arena: one-off assessments, and a willingness to change institutional arrangements.

But, you may say: this is a limited analysis; these are mere appearances. We should engage with larger political fictions such as the state or patriarchy. The Hawke government's moves on disability parallel some of the shifts Dale (1990) describes in the Thatcherite project on education, and yes, a socio-political perspective which focuses on specific struggles leaves women's place in disability largely unexamined. Australian and other women with disabilities (Driedger, 1989), have increasingly recognized their issues differ from those of men.[12] As Barton (1991) suggests, feminist analyses may have much to offer, including Pateman's (1988),[13] Meekosha's (1990), and Meekosha

and Jakubowicz's (1991). But where do these analyses leave potential peer workers?: waiting in the wings, while others seek out patriarchy and the state?

The debates on socio-political perspectives are much wider than this. We face an amazing array of choices: collective democratic projects; long-term social democratic projects; limited, long-term democratic projects; social movements and their critics; the view that the city-citizen game may be outmoded (Hindess, 1991 b:7); and that ideas of democracy and socialism have little to offer in 'the internalization of economic activity' (Hindess 1990a).

Risk as a conclusion?

In this political flux, a perspective from limited projects can usefully warn of the risks and opportunities which government interventions present to Australians with disabilities. This analysis is both unheard in many disability arenas and strongly resisted by others whose objectives it challenges, as Newell (1991) suggests. Risks inherent in 'choice' without a critique of neo-liberalism, in 'consultation' without egalitarian conditions for taking part (Furrer, 1990), in 'participation' when it becomes representative bureaucracy (Rizvi and others, 1987; Fulcher, 1989) and legitimation. Consultations on the Ronalds' (1989) rationalist report on the 'rights' of residents in nursing homes to, among other things, sexual relations and choice of doctor, did not avert the Catholic Bishops' intervention. The issue disappeared from the media; the funding agreement was signed, an addendum appended. There are significant actors other than government and arenas other than government where debate may profoundly affect the lives of people with disabilities and exclude their voice: a member of DPI may be the first locally to challenge the rationalist ethics of utilitarianism in medical debates on genetic engineering. The Australian debate on infants with disabilities may be better known in Europe (see Furrer, 1990) than it is in some local disability groups. The irrationalities of economic rationalism are not well understood; category politics such as disability (Liggett, 1988) can entrench disadvantage, as the stand-off mechanisms in the Victorian Ministries of Housing and Education show (Fulcher, 1990b). These analyses derive from a limited struggles perspective. This is a start.

So disability rights and voice: yes, some of the time. And all of the time; which political move? There are no clear trajectories. Rights may gain formal rationality, formal rationality may precede substantive rationality, but participation without substantive moves may distract the project. The idea of rights has made 'new matters negotiable', but political formalisms such as 'equity' and 'justice' have little to offer specific activities. To say that socio-political perspectives other than those from people with disabilities are relevant, means only that all of us act on the basis of limited perspectives. Unless we canvass widely, we risk the feasibility of our projects. And risk may be a useful concept for our times: it unites mainstream social theorists and those further

to the left.

Endnotes

[1] One official rate for northern Victoria (Australian Bureau of Statistics, from data obtained verbally on 29 September 1991). This is higher than the official State and national average. Academic sources suggest the rate in Victoria is nearer 20 per cent (*The Australian*, September 21-22, 1991).

[2] As of June 1990 (Australian Bureau of Statistics, from data obtained verbally in September 1991).

[3] The Australian branch of Disabled People International, unlike their British counterparts, reject the term 'disabled people'.

[4] '...does not apply to...discrimination on the ground of impairment, if...(it) requires or would require special services or facilities that in the circumstances of the case cannot or could not reasonably be made available...' (4) (g) *Equal Opportunity Act* 1984).

[5] In a second hearing in the Supreme Court on 5 February 1991, the matter of Waters vs. the Transport Corporation, the Transport Corporation vs Waters, was reserved and the judgment six months later, 'not yet handed down'.

[6] Department of Social Security.

[7] MERGE (Melbourne Evaluation and Research Group) meets monthly.

[8] Do they arrive hot, is not, it appears, a simple question. Well, it has no simple answer in this service.

[9] In a conversation with Stephen Ball in Melbourne, February 1991.

[10] The skilling debate, perhaps more than examinations, implies an individual's skills can be measured.

[11] See Hindess (1982) and Fulcher (1989) for broader discussion.

[12] See *DRC Bulletin* Number 62, June 1991:17, *DEAC News*, April 91:18.

[13] See also Dean (forthcoming).

Bibliography and References

Abberley, P. (1987). 'The Concept of Oppression and the Development of a Social Theory of Disability', *Disability, Handicap and Society*. 2, 1, pp. 5-20.

Abberley, P. (1990). *Handicapped by Numbers: A critique of the OPCS Disability Surveys*. Occasional papers in sociology no. 9, Bristol Polytechnic.

Ball, S. J. 'Management as moral technology: A Luddite Analysis' in S. J. Ball (ed) *Foucault and Education: Disciplines and Knowledge*. London, Routledge, pp. 153-66.

Beck, U. (1989). 'On the Way to the Industrial Risk Society? Outline of an Argument', *Thesis Eleven*, 23, pp. 86-103.

Beilharz, P. (1986). 'The left, the Accord and the future of socialism', *Thesis Eleven*. 13, pp. 5-10.

Beilharz, P. and Watts, R. (1983). 'The discovery of corporatism' *Australian Society*. 2, 10, pp. 27-30.

Cresap, a Towers Perrin company (1990). An *Analysis of Disability Services Funding and Planning for Non-government Organization Providing Disability Services in Victoria*. Part A. Prepared for VICROD, November.

Dale, R. (1991). 'The Thatcherite project in education: the case of the City Technology Colleges', *Critical Social Policy*. 27, Winter, pp. 4-19.

Dean, M. (forthcoming). 'Citizenship, Universalism and Difference: Carole Pateman's Dilemma'. (A review essay), *Theory and Society*.

Disability Employment Action Center, *DEAC News*, March 1990; *DEAC News*, April 1991; *DEAC News*, August 1991.

Disability Resource Center, *DRC Bulletin*, Number 62, June 1991.

Dow, G. (1991). 'What Do We Know About Social Democracy?' paper prepared for National Social Policy Conference, Social Policy Research Centre, University of New South Wales, Sydney, 3-5 July, 1991, typescript, p. 34.

Driedger, D. (1989). *The Last Civil Rights Movement*. London, Hurst and Company.

Equal Opportunity Board, Melbourne. P. Waters and Others, Complainants and The Public Transport Corporation Respondent, Further Reasons for *Decision*, re Order of 9 May 1990, typescript 14 pp.

Equal Opportunity Board, Melbourne. P. Waters and Others, Complainants, and The Public Transport Corporation Respondent, *Decision*. Copy made 28 March 1990, typescript 45 pp.

Equal Opportunity Board, Melbourne. P. Waters and Others, Complainants and the Public Transport Corporation Respondent, *Further Reasons for Decision*, re Order of 9 May, typescript 14 pp.

Equal Opportunity Board, Melbourne. P. Waters and Others, Complainants, and The Public Transport Corporation Respondent, *Decision*, copy made 28 March 1990, typescript 45 pp.

Frankel, B. (1987). *The Post-Industrial Utopians*. Blackwell Polity Press.

Fulcher, G. (1989). *Disabling Policies? A comparative approach to education policy and disability*. Lewes, Falmer Press.

Fulcher, G. (1990a). 'Policy, Practice and Social Theory: Towards an Agenda', in Jamrozik, A. (ed) *Social Policy in Australia: What Future for the Welfare State?*, volume 3, SPRC Reports and Proceedings, Kensington, University of New South Wales.

Fulcher, G. (1990b). 'Disability Issues and the Olympic Bid: Moving On', report to the Social Impact Assessment Panel of the Melbourne Olympic Committee, typescript, 32 pp. June.

Furrer, H. (1990). 'Abortion and infanticide, or quality of life?' *European Journal of Special Needs Education*, 5, 1, pp. 44-47.

Gauchet, M. (1991). 'Democratic Pacification and Civic Desertion', *Thesis Eleven*, 29, pp. 1-13.

Giddens A. (1990). *The Consequences of Modernity*. Stanford, Polity Press.

Glendinning, C. (1991). 'Losing Ground: social policy and disabled people in Great Britain, 1980-90', *Disability, Handicap and Society*, 6 ,1, pp. 3-19.

Hindess, B. (1978). *The Use of Official Statistics in Sociology: A Critique of Positivism and Ethnomethodology*. London, Macmillan.

BEST COPY AVAILABLE

Hindess, B. (1982). 'Power, Interests and the Outcomes of Struggles', *Sociology*, 16, 4, pp. 498-511.

Hindess, B. (1990). (ed.) *Reactions to the Right*, London, Routledge.

Hindess, B. (1991a). 'Imaginary Presuppositions of Democracy', *Economy and Society*, 20, 2, pp. 173-95.

Hindess, B. (1991b). 'Power and Rationality: the western concept of political community', paper presented at *Thesis Eleven* Conference: Reason and Imagination, Monash University, August, typescript 11pp.

Hirst, P. (1990). 'Democracy: Socialism's Best Reply to the Right', in Hindess, B. (ed) *Reactions to the Right*, London, Routledge.

Klugman, K., Grant, B., McGuigan, Lombertson, D., (1991). 'From Isolation to Opportunity: Applying Communication and Information Technology to Facilitate the Placement of People with Physical Disabilities into Open Employment', *Circuit Working Paper*, August.

Liggett, H. (1988). 'Stars aren't born: an interpretive approach to the politics of disability', *Disability, Handicap and Society*, 3, 3, pp. 163-75.

Meekosha, H. (1989). 'Research and the State: Dilemmas of Feminist Practice', *Australian Journal of Social Issues*, November, pp. 249-68.

Meekosha, H. and Jakubowicz, A. (1991). 'Repetition strain injury: The rise and fall of an "Australian disease"', *Critical Social Policy*, 31, pp. 18-37.

Newell, C. (1991a). 'In Support of the Advent of Disability Studies in Australia', *Australian Disability Review*, 2/91, pp. 25-6.

Newell, C. (1991b). 'Selected Ethical Implications of Genetic Engineering for People with Disabilities', Grand Round and Paper presented to the Kingsley Fairbridge Child Development Unit 1991 Conference, September 4, 1991, Adelaide Children's Hospital, typescript, 16 pp.

Oliver, M. (1990). *The Politics of Disablement*, London, Macmillan.

Parent Voice (1991). 'Draft Model Policy Integration in Victorian Education', *Noticeboard*, June.

Pateman, C. (1988). *The Sexual Contract*, Cambridge, Polity Press.

Pathfinders Consultantcy pty. ltd. (1990). *An Investigation of Issues Associated with the Participation of People with Disabilities in Skillshare*, 73 pp.

Pusey, M. (1991). *Economic Rationalism in Canberra*, Cambridge, Cambridge University Press.

Rizvi, F., Kemmis, S., Walker, R., Fisher, J., Parker, Y. (1987). *Dilemmas of Reform: An Overview of Issues and Achievements of the Participation and Equity Program in Victorian Schools 1984-85*, Geelong, Deakin University.

Shapiro, M.J. (1988). *The Politics of Representation: Writing Practices in Biography, Photography and Policy Analysis*, Wisconsin, The University of Wisconsin Press.

Touraine, A. (1989). 'Is Sociology Still the Study of Society', *Thesis Eleven* 23, pp. 6-34.

Victorian Council of Social Service, *VCOSS Annual Report 1991*.

Wickham, G. 'Theorizing Sociology in the Face of Post Modernism', School of Social Sciences, Murdoch University, typescript 26 pp.

Policy Documents

Cass, B. et al (1988). *Social Security Review, Towards Enabling Policies: Income Support for People with Disabilities*, Canberra, Australian Government Printing Service.

Commonwealth Disability Anti-discrimination Legislation Committee, (n.d. current September 1991). *National Disability Discrimination* Legislation: A Discussion Paper, typescript, 20 pp.

Office of Disability, Commonwealth Department of Community Services and Health (n. d. but May 1991) 'User rights and responsibilities for people with disabilities: An issues paper, 12 pp. with attachments.

Ronalds, C. (1989). *Residents' Rights in Nursing Homes and Hostels: Final Report*, to the Department of Community Services and Health, Canberra, Australian Government Publishing Service.

Summary of New Directions (1985). Report of the Handicapped Programs Review', Canberra, Australian Government Printing Service.

Acts

Commonwealth
Disability Services Act 1986
Social Security (Disability and Sickness Support) Amendment Bill 1991

Victoria
Intellectual Disability Services Act 1986
Equal Opportunity Act 1984

CHAPTER FOUR

U. S. Commentaries

Joseph Stubbins, Ph.D.

Margaret A. Nosek, Ph.D.

Frank Bouve, Ph.D.

Mary Ann Carroll

James Charlton

David Pfeiffer, Ph.D.

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Joseph Stubbins, Ph.D.

Dr. Stubbins has been involved in counseling and rehabilitation for most of his life working with disturbed adolescents, high school and college students, drug abusers and mentally ill adults. He began the Master's Program in Rehabilitation Counseling at California State University where he remained until retiring in 1986. Currently, he is a member of a county Mental Health Advisory Board in California where he has confronted many of the problems mentioned here.

Disabled persons are marginalized individuals, suffering from low social status, unemployment, under-employment, and are voiceless on services and policies that concern their welfare. Their marginalization is more problematic and formidable than their medical and psychological dysfunctions. People with disabilities are a disenfranchised and powerless minority, and as such experience many of the same obstacles to fairness and equity as ethnic minorities, women and the poor. In brief, a socio-political perspective seeks to balance the prevailing modes of viewing disability problems in terms of person-units by recourse to analyzing the roles played by social and political institutions and nondisabled persons in marginalizing people with disabilities. For those willing to struggle with Foucault's abstract writing style, his works are a rich source of social theories for the subject under discussion. I trust that this is a fair summary of the common theme of Barton's, Fulcher's and Ballard's papers.

These writers hold academic posts and it is fair to assume that they visualize their readers as other academics and professionals involved in education, training, or research of psycho-social care givers and perhaps have given less thought to how community leaders might interpret their writing. This assumption is suggested by the writing style that at times would strain the interest and commitment of the ordinary reader. Academics in the United States have shown meager interest in socio-political perspectives far less than some consumers or clients, family members, advocates and some civic leaders. A professor addressing a mixed audience of colleagues and political activists representing groups of disabled people on the subject of these papers would notice the enthusiasm of the latter and the tight-lipped bored expression of the professionals.

Ballard's paper illustrates that it *is* possible to write about a complex subject in a manner that is condensed, clear, and convincing without sacrificing scholarship. The ease and pleasure of reading his essay gives little hint of the effort that probably went into a finished product that shows no trace

of scissors and paste. His anecdotal material is cogent and relevant. His use of terms such as "ecological" to explicate a system's approach to disability is one example of his utilizing terms that have become household words. We who subscribe to a socio-political point of view must struggle against the fear that popular writing, using minimal technical terms, compromises our intellectual status.

Fulcher is annoyed with economic rationalism and the centralization of welfare services for disabled persons in Victoria, Australia. No doubt, these are legitimate complaints. However, some suggestions regarding the complex process of pointing to remedies and finding allies that would support the necessary reforms would have been more appropriate. California advocates for the mentally ill had problems with excessive centralization that created difficulties similar to what Fulcher pointed out. Recent legislative changes at the state level and others pending at the federal level are resulting in substantial decentralization. Hence there will be many more local initiatives and experimentation than was previously possible. It required over two years of negotiation with state officials and political lobbying to effect the improvements.

Since the largest share of the funding for welfare programs comes from state and federal coffers, local authorities will maintain records and make reports to the State capital to ensure that funds are spent according to guidelines. If this is "economic rationalism" then Californians will have to learn to live with it. Welfare services are not so esoteric or elusive that their benefits cannot be captured and measured by methods of evaluation and accounting familiar to social scientists.

It is possible that Fulcher lost sight of the fact that she was writing for an *international* readership of administrators, professional providers and researchers most of whom are directly involved in service programs. The meat of her paper was obscured by her use of numerous acronymic references to Australian programs and her injection of epistemological issues.

Clearly, the three papers criticize the prevailing ways in which persons with disabilities are viewed, diagnosed, conceptualized, advised, helped, and treated on the one hand; and also on how they are misunderstood, misdiagnosed, mistreated and even oppressed. The object of their criticism is a prevailing paradigm that I would characterize as a conception, world view, or a perspective that regards individuals with disabilities as self-contained, captains of their ships, and totally in charge of their destinies. The writers are blaming romantic or rugged individualism for the depreciated social and economic status of people with disabilities. And furthermore, unbridled individualism is much more than a narrow, unsophisticated philosophy peculiarly supportive to the power elite, it is prejudicial to the vast majority

of people with dysfunctions because it paints them as *natural* losers in a Darwinian race for success and survival.

The media entertain us with examples of persons sans legs, arms, sight, hearing, and even diminished intellectual capacity who have succeeded in spite of their handicaps as in the Olympics for the Handicapped. But all this hoopla is in the service of buttressing the notion that each one of us is capable of overcoming any obstacle. There is little attention given to the fact that 75 percent of seriously disabled individuals are unemployed and how governmental economic policies affect the employment prospects of persons with disabilities. All three writers are aware of the prevailing bias of accounting for individual differences in the status of people with disabilities by reference to personality dimensions and with little attention to ecological factors.

Persons with disabilities are treated as spoiled goods in the market place. Socio-economic differences are stubborn dimensions of daily life notwithstanding some social and economic mobility. A vast array of mechanisms are in place to ensure economic and social stability. Disabled persons tend to be at the bottom of this hierarchy and as such are voiceless among their various caregivers: physicians, psychiatrists, psychologists, social workers, physical therapists, paraprofessionals and personal care attendants. Sometimes disabled persons are treated as having only slightly better judgment than children. This paternalistic, patronizing attitude has resulted in the caregivers' 'charges' losing their dignity or simply becoming angry and depressed. Barton seems to search for the causes of such social relations in the structure of society and presumably finds that it mirrors the social relations of capitalist society.

Though there is no conspiracy among the powerful to maintain people with disabilities in a menial status, one might assume that from Barton's analysis. Citizens go about their business as best they can and accept their world unproblematically. They behave this way not because they are stupid or uncaring, but because the struggle for survival and self-realization consumes all their energy and will continue to do so in this era in which two breadwinners are needed to support a household. Disabled Britons with a university education who have their own organization presumably see themselves as having objectives different from those with less education, and shall we say, take care of their own first. Citizens with disabilities also are capable of the same prejudice and altruism as the non-disabled people; they experience the same psychic deflation as mainstream citizens and minorities do in this age of diminishing standards of living.

Barton's conflict theory of society may be a useful analytic device, but he has given few strategies that would build a strong constituency to produce the liberation of disabled persons. If resources are limited, then improvements in the economic status of people with disabilities must come from those

who have more. For instance, how would we go about the business of raising the consciousness of persons? How would we raise the money and win the support of public spirited citizens? And how do we go about building coalitions with similarly disadvantaged constituencies?

In seeking support, the community of disabled people would have to decide who are friends, and dependable or potential allies. I refer to the following constituencies: friends and relatives of people with disabilities, elected officials at the local and state levels, certain professionals that serve people with disabilities, professionals who themselves are disabled, management and employees of governmental agencies, civil service workers, charitable foundations, the most affluent citizens, and public spirited citizens. In the process of interacting with these real people, few of them would understand what was meant by "the disabled are an *oppressed* group"; at best, it would leave them perplexed. We brush against these persons daily and thus have opportunities to influence the tenor of our relations. How helpful, therefore, is the warning given by Barton, " .... (we must) struggle against any crude reforms, unwitting complicity, or the softening of the endeavors that will be required if the empowerment of disabled people is to be real and effective." Such a policy equates the struggle for incremental changes as selling out to the enemy.

That does not seem like good advice. Precisely because most people with disabilities have been handicapped by fewer educational opportunities and life experiences, they are not likely to benefit from confrontation. The achievements of well organized disability types suggest the need for more varied ways of struggle to be mentioned later. The progress achieved by advocates for developmentally disabled people in the United States in the last 40 years is worth studying. The movement's early years was marked by hostility toward most professionals. But that phase lasted only a few years. The cooler heads won over and built bridges to professionals of various disciplines, leaders in the media, politicians and so on. Their economic and legislative victories achieved on behalf of children and adults are models that any disadvantaged group should emulate.

It is easier to mobilize dissatisfied people against a real enemy or a scapegoat than to have them embark on more constructive modes of conflict resolution. Since dissatisfaction, anger, frustration and envy are, so to speak, first cousins, it might be defensible to mobilize people with disabilities against oppressors as a strategy for action. Such a strategy has a limited utility, however. Sooner or later, disabled persons must learn the arts of playing the political game — at the local level first and later at regional and national ones. Improvements in the quality of their lives will result from garnering real limited achievements in the form of greater funding for rehabilitation, access to housing and jobs, and basic civil rights.

Professional care givers are socialized into a ready-made world connected to their occupational roles that provide them with a tolerable standard of living, positive value attitudes toward socially disadvantaged people and ethical perspectives. Because of these advantages, they should be sensitive to each individual's potential of being oppressor and oppressed. Likewise, professionals might be expected to have insights into the duality of self-seeking and altruism that characterize everyone. Hopefully, professionals can help others transcend this duality by means of reflection, communication, dialogue, analysis, mutual respect, negotiation, compromise and tolerance; thus, both to give and receive in their relations with their clients. Such a prospect allows room for optimism that professionals can not only be allies but also leaders in the political and social aspirations of seriously disabled persons. Any attempt to storm the credibility of members of the professional establishments, of the politicians, and of any of the stakeholders in the disability business, would backfire. Those in power usually are more savvy about how to defend their interests than disabled people are in exposing them. However, the means of building viable political coalitions and strategies for those with serious handicaps is really beyond the scope of the papers under discussion.

In the United States, there is a substantial body of literature on the social and political outlook on disability issues, some of it dealing with the viewpoint of consumers, clients and self-help advocates. A sample of such literature follows.

References

'Psychology in the public forum.' (1990). Four Articles. *American Psychologist, 45*, 6, pp. 751-776. (Rehabilitation psychology has been a recognized specialization in the US for 40 years. These articles provide an overview of the varied roles of rehab psychologists and the issues they face in the larger society.)

Stubbins, J. (1989). 'The interdisciplinary status of rehabilitation psychology.' *Rehabilitation Psychology, 34*, pp. 207-215. (Criticizes psychology for its tunnel vision and calls for transdisciplinary inputs for a fuller understanding of disability problems.)

Stubbins, J. (1988). 'The politics of disability.' *Attitudes toward persons with disabilities*., Yuker, H. E. (ed.), pp. 22-32. New York: Springer Publishing. (Calls upon professional providers to pay more attention to the social, economic and political factors that keep persons with disabilities in a marginal status.)

Stubbins, J. (1985). 'Some obstacles to policy studies in rehabilitation'. *American Behavioral Scientist, 28*, 3, pp. 387-395. (Deplores the fact that few academics and researchers expose their students to policy issues and discusses why they shy away from this responsibility.)

Stubbins, J. (1984). 'Rehabilitation services as ideology'. *Rehabilitation Psychology, 29*, pp. 197-202. (While rehabilitation services are presumably based in science, they also embody ideological elements that consumers should be aware of.)

Stubbins, J. and Albee, G.W. (1984). 'Ideologies of clinical and ecological models'. *Rehabilitation Literature, 45*, pp. 349-353.

Stubbins, J. (1982). *'The Clinical Attitude in Rehabilitation: A Cross-cultural View'*. Monograph #16. International Exchange of Experts and Information in Rehabilitation. World Rehabilitation Fund. (In this WRF-IEEIR monograph, the author, having spent a year in the UK looking at the British rehabilitation system and attitudes, reflects on the rigidity of the clinical attitude in the U.S. and how rehabilitation practitioners, administrators and researchers have been little influenced by sociology, economics and political science.)

Weiss, Carol H. (1991). 'Linking evaluation to policy research'. *Foundations of program evaluation: Theories of practice*. pp. 179-224. Sage Publications, Inc: Newbury Park, California. (This is an excellent overview of why even carefully designed evaluation of social welfare programs has had so little impact on policies and practices, and contains insights into the politics of stability and change in service delivery. But Weiss does not deal with disability programs as such.)

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Assistant Professor of Baylor College of Medicine in Houston, Texas. Dr. Nosek conducts research on issues related to independent living and disability policy. She has published widely and lectured extensively both nationally and internationally. Her advocacy through disability rights organizations has brought down barriers at many levels of society. She has had an IEEIR fellowship studying personal assistance in Japan.

I am always uplifted to see someone become enlightened about disability. Having been effectively insulated from the effects of disability during my upbringing by two very enlightened parents, I was dumbfounded when I hit the real world and realized that in many people's minds I was characterized more by my physical characteristics than by my talents. I found this not only in educators when, during my audition for music college, I was nearly rejected because I played the oboe from a wheelchair (luckily, the oboe professor observed that I played it rather well and convinced the others to admit me), and in public facilities when I could never live in the same apartments or ride the same buses as my friends just because I used a wheelchair, but especially in a whole system of social services that were supposedly set up to help me.

I never experienced so much focus on my disability until I was introduced to the rehabilitation system. After being evaluated, categorized, and planned for, it was all I could do to gather what self-esteem I had left to convince myself that independence was not as hopeless as they were trying to convince me it was. It was pure force of will that enabled me to break the cord and go out on my own. In the difficult years that followed, trying to find paths around the innumerable barriers that society had in place for me, I accumulated considerable evidence supporting my contention that it wasn't my disability that held me down, it was society's response to it; and that the strongest counteracting force was my own fighting spirit. I was so driven by the contradiction between this notion and the operating assumptions of the 'rehab' system, that I decided to do something about it by changing my field of study and becoming a 'rehab' professional myself. I even made this hypothesis the topic of my doctoral dissertation and found that among a group of people with widely differing degrees of disability, the single factor that related most strongly to their independence was their psychological make-up. It wasn't their disability that made the difference to them.

So you can understand why I rejoiced when I read Dr. Barton's diatribe against the traditional medical approach to disability and embrace of the

socio-political approach with religious fervor. Should the policy makers in his country also see the light, there may be hope for meaningful change, as there has been in the United States through the *Americans with Disabilities Act* and other recent pieces of legislation. However, there are features of this argument that cause me to ponder. It seems riddled with paradoxes.

Adopting the socio-political approach to disability necessitates that one accept people with disabilities as oppressed. I certainly have no objection to that. To further state, however, that we are "powerless and worthless in an alien society" cuts to the core. Yes, I am powerless to mount steps. Yes, I am powerless to make quick and sweeping changes in an archaic rehabilitation system; yes, that system did its best at one time to make me feel worthless; and yes, this society seems pretty alien given my needs. But I never in my life felt truly powerless or worthless. I think if you asked every one of the 43 million of us in the U.S., most would say the same thing; but to analyze our lives in comparison with the ordinary public, we are certifiably oppressed. The missing variable in this analysis is the personal element—the fighting spirit, the enlightened parents, the drive to reach one's goals no matter what. If only we could revolutionize our systems to maximize these characteristics instead of only minimizing the physical ones.

Another paradox is the financial aspect of the socio-political approach. Nobody seems to want to spend money on us (well, certainly not enough money), yet we are a highly valued commodity to some sectors in our society. As Dr. Ballard pointed out in discussing education, economics sanctions discrimination. The same holds true in the removal of architectural and environmental barriers and modifying programs and policies to allow equal opportunities. The cost of change is the first issue to arise, with virtually no attention given to the financial consequences of continuing current practices of discrimination and exclusion. A brief look at the nursing home industry, on the other hand, reveals people with disabilities as a gold mine. How many lives of quality have been sacrificed on the cross of institutionalization to ensure economic security for nursing home owners and their lobbyists? An effective redistribution of the money currently perpetuating non-productive and non-quality of life services could fund our ideal of consumer-controlled, community-based services for everyone ten times over.

Equal opportunity itself is a paradox, as Dr. Barton so insightfully points out. It connotes equal access to the same ineffective, inefficient, self-limiting 'opportunities' that everyone else has. Its truer meaning is to be taken to a higher scale—challenging the status quo and establishing systems that respond to individual needs and enhance potential for lives of quality, independence, and productivity.

Frank Bowe

Frank Bowe, a professor at Hofstra University, Hempstead, N.Y., is a former RSA Regional Commissioner, appointed by Justin Dart in 1987. Bowe was the first executive director of the American Coalition of Citizens with Disabilities, Inc. He has served as Chairperson, U.S. Congress Commission on Education of the Deaf. Dr. Bowe's IEEIR-sponsored visit to Japan and Korea was undertaken at the request of Senator Tom Harkin (D-IA) in order to understand the views of TV manufacturers before agreeing to introduce legislation recommended by Dr. Bowe's commission. Mr. Harkin later introduced, and the Congress passed, (PL 101-431) the Television Decoder Circuitry Act of 1990. That legislation has resulted in commercial TV sets that are caption-chip equipped.

Reading Barton's paper brought to mind the old saying, "The more things change, the more they remain the same." As I have tried to point out (Bowe, 1990), independence and self-determination for people with disabilities anywhere in the world are most probable where we as individuals with disabilities have established cogent social-policy reasons why society should respect our desire to decide our own fates. What we see reflected in Professor Barton's paper are some of the consequences of not doing that. People with disabilities in the United Kingdom under the 1970s-era Labour government failed to put forward a basis for national consensus behind disability self-determination. In part, I suspect, this was due to the fact that the 'public' education system in England did not educate people with disabilities for lives of self-sufficiency and independence.

To an extent that would appall an American, youth in Great Britain do not go to college, especially if they have disabilities. Few leaders of England's disability population had established credentials as people who 'have to be seen' in the formulation of public policy. Thus, with the advent of Margaret Thatcher and the conservative movement, the British population of people with disabilities was not sufficiently visible and politically powerful to insist that the constituency determine their own fates within the context of overall governmental policy. The decisions were made, rather, by governmental officials with paternalistic attitudes toward people with disabilities.

In Sweden and Denmark, it seems to me, we have seen an opposite extreme. There, the State has given over most of the control of many disability policies to organized representatives of people with disabilities. In deafness, for example, it is not uncommon to find the associations of deaf adults determining education policy for deaf children — and, even choosing school superintendents! As the Scandinavian countries cope with contracts emerging

from decades of over-generous government, we may see the kinds of pull-backs Barton reports in the United Kingdom. I hope not, but I can see it happening.

Justin Dart keeps describing the *Americans with Disabilities Act* (PL 101-336) as "the world's first comprehensive civil rights legislation for individuals with disabilities." He has a point. What we did with ADA is do-able elsewhere in the world, certainly in the United Kingdom. But we got ADA passed because we had a phalanx of well-educated, experienced activists with disabilities, Justin certainly included, who had established their credentials in Washington, DC. It is, for me, unimaginable that the U.S. Congress would enact legislation affecting people with disabilities without first consulting with people like Justin Dart.

We have not gone as far as have some other countries in the world — U. S. disability organizations do not administer government programs nor select their administrators — but we have created a system in which our views are considered in the formulation of government policies. And we did this in America largely by making our case for self-determination. We said that if barriers are removed, and policies changed, we would be much more likely as a population to become employed, self-sufficient, tax-paying citizens. This argument is as old as Mary Switzer, who headed the Vocational Rehabilitation program under Presidents Eisenhower, Kennedy and Johnson. It is, in many respects, what we in the United States would call a 'Republican' argument, and people in the United Kingdom would refer to as a 'Conservative' argument. Even so, the fact remains that government has an interest in promoting this vision, precisely because the population of people with disabilities is offering *a quid pro quo*: we agree that if we are ensured full and equal access to society and full protection of our rights to nondiscriminatory treatment in all aspects of life, we will in return, as a population, burden the American taxpayer much less than we would were society to remain inaccessible and our rights nonexistent.

This is how I have seen things for years now. That is why what Barton presents in his paper seems to be nothing new. The population of people with disabilities in the United Kingdom must assume some of the burden for the sad state of affairs he describes — and some of the responsibility to rise up to take part in shaping post-Thatcher social policies.

Reference

Bowe, F. 'Disabled and Elderly People in the First, Second and Third Worlds.' *International Journal of Rehabilitation Research*, v. 13, (1990), pp. 1-12.

Mary Ann Carroll

Mary Ann Carroll is the former Director of Special Projects and Research at United Cerebral Palsy of New York City. In this capacity she designed and administered technology-based education to pre-school and school-aged children. She is also a Ph.D. candidate and former adjunct professor at New York University, and a fellow of the International Exchange of Experts and Information in Rehabilitation. She now lives and works in the state of Florida.

Professor Barton's paper was written within the context of a British socio-political perspective. This American commentator cannot make any judgement to its validity or currency within that context. I will, however, react to its impact on me as a person who has had personal and professional experience with disability in the United States.

On first impression, Barton's well written paper is not saying anything new or revolutionary. Having said that, I will immediately follow by saying that the issue of studying, treating, and culturally including disability from a socio-political perspective—however well articulated by disability advocates of the last decade or more—in reality, still lags behind any socio-political theories that have been posited.

Paternalistic, medical, professional driven models of service still persist in the community, in professional education, in public education, and in the broad breadth of rehabilitation services provided to individuals with disabilities and their families. Meaningful active participation of consumers in policy and decision-making in most institutions is still, for the most part, more symbolic than real.

It is believed that political activism by disability activists over the past two decades has resulted in measurable progress in this country. There is an increased consciousness in the society regarding the rights and potentialities of people with disabilities as seen in more progressive legislation regarding the previously institutionalized, educational inclusion, and even the beginning of a paradigmatic shift of seeing an inaccessible environment as handicapping rather than seeing the individual as statically environmentally resistant. It was heightened socio-political activism that culminated in the passage of the recent landmark legislation - the *Americans with Disabilities Act*. Nevertheless, the task of changing hardened stereotypes, institutions, and models of service still needs to go on apace.

Areas of concern for the future include the need for revitalization of the activist movement, building a legacy of leadership and serious consideration

of new ways of widening the dialog (so well described by Stubbins) from confrontation to conflict resolution. Finally, Barton's reference to a "free market ideology" has got to be better understood and expanded upon because it is believed that in that portion of his paper lies the new barriers to understanding what needs to be examined and politicized in an ever growing free market ideology and global economy.

James Charlton

James Charlton has been employed in a leadership position at Access Living for the last six years. The positions he has held include the Director of Programs and currently, Executive Vice President. In both he has had administrative responsibility for most of Access Living's staff; in the latter, he functions as chief operating officer of the center.

In addition, for the last eleven years he has been deeply involved in the disability rights movement both locally and nationally. He has been most interested in issues as they relate to the continued segregation of the disabled community and how and why disability related organizations have emerged to confront discrimination.

Having travelled throughout Central and South America and, through an IEEIR fellowship) to Zimbabwe, Charlton has been able to have discussions with many disabled activists on how they perceive the barriers to disability rights and what strategies they are employing to overcome them.

As a longtime political activist, I was impressed by Len Barton's effort to politicize disability. Too often, the struggle for disability rights is consigned to the terrain of changing attitudes. Attitudes and politics, oppression and economics are inextricably linked, except when it comes to disability, then 'mysteriously' these are decoupled. Fortunately, Len Barton explores the phenomenon of oppression, necessarily analyzing where all the backward attitudes toward disability come from.

In developing his analysis, Barton makes two important points at the outset: the pejorative centrality of the medical model and the corresponding absence of the voice of disabled persons. These are also fundamental criticisms we have in the U. S. precisely for the reasons Barton cites: the logic necessitates the dehumanization and marginalization of people with disabilities.

My guess is that a dozen years of Reaganism has a close parallel in Britain. The political paradigm has as its centerpiece the individual: the individual with free will confronting a marketplace of choices. Ergo, if the individual experiences discrimination it is either his/her fault or the result of an isolated incident. This has always played a role in supporting the status quo. It is a necessary part of the ideological supports propping up the marginalization of millions of people.

Many disability rights activists also fail to see these necessary links. Often, discrimination is talked about in a political vacuum in terms of bad people with bad ideas. This fundamental mistake leads many people with

disabilities, even those who are active in our struggle, into a political dead end. By resisting disability discrimination in isolation from other forms of oppression, many in the disability rights movement have no strategic view of where it all leads and what might deal with our discrimination more systemically. Disability awareness and public education replace organizing a political movement utilizing demonstrations and political action to confront the political elites.

Fortunately, Len Barton's argument for a political perspective of disability begins to expose the limits of this depolitical perspective. Barton yanks disability discrimination out of the realm of psychology and locates it correctly in politics. Barton understands that the discrimination people with disabilities experience is not because individuals have backward attitudes and biases but that the political system benefits from marginalizing people.

Without a political perspective and the systemic analysis this produces, there cannot be a long term strategic view that liberates people with disabilities. We will continue to be the poorest, most unemployed group in the U. S. (and around the globe) regardless of the *Americans with Disabilities Act*, until the political demands of our community are taken seriously. This is a function of political power.

Many years ago, I used to say that the biggest challenge disabled people faced was changing the backward attitudes of able-bodied people; now I believe the first thing we must do is to change disabled people's minds about our themselves. Only until we have a political consciousness as people with disabilities and are organized in our thousands and tens of thousands will we have some political power. Len Barton's chapter in this monograph makes a contribution to this process.

David Pfeiffer

David Pfeiffer, Professor of Public Management at Suffolk University in Boston, was the Massachusetts State Director for the White House Conference on Handicapped Individuals, the first Chair of the Massachusetts Advisory Council on Disability, and serves as President of the Society for Disability Studies.

What is striking about Barton's paper and the two comments on it by Gillian Fulcher of Australia and Keith Ballard of New Zealand is that the paramount issue within the Disability Community in the United States is also of major importance in the United Kingdom, New Zealand, and Australia. From personal conversation and reading, I know that it is also a major issue in Canada and in the rest of Western Europe. In the remainder of the world (with one or two exceptions) there is a problem of lack of care and equipment for persons with disabilities because of a lack of resources in general. In what may be called Western nations (such as those countries named) the problem is whether professionals control the resources or whether members of the Disability Community control them.

Let me quickly admit that there are persons with disabilities who are professionals and who are part of the Disability Community. There are also persons without disabilities who are professionals who are also members of the Disability Community. And there are persons with disabilities who are professionals and who are not part of the Disability Community. It is not easy to place each person in a specific role since there is some overlap. Nevertheless, the question of control of resources is the key issue today in the United States and other countries.

This issue is expressed in terms of providing personal care assistants for many persons. For others, it is expressed in terms of adequate health insurance. For yet others, it is seen in whether quotas should be required under the employment discrimination part of the *Americans with Disabilities Act*. And for still others it revolves around mainstreaming in education. Although the immediate context may vary, the key issue is who will make the decision.

Barton discusses the role which definition of disability plays in this problem. According to him, in the United Kingdom the crucial factor in policy discourse is "the absence of the voices of disabled people themselves" because persons with disabilities are defined as having nothing to contribute. In the United States we are beyond this point because enough of us had the personal resources to organize the Disability Community and make it a

political force. The *Americans with Disabilities Act* nationwide and the existence of laws in some states are witness to the impact of the organizing which has occurred.

In the United States, for some time, disability (then termed handicap) was defined as being unemployed because of an impairment. Once the person was employed, it evidently was thought, the impairment disappeared. As a person with a disability who was either employed or a student or both since the age of six years, I always marvelled at the ignorance of such a definition. Gradually, the definition shifted to the position that disability meant the existence of an impairment which prevented the person from carrying out some function in a normal way.

Again, I marvelled at the ignorance of such a definition. What is the 'normal' way to earn a living, to travel one mile (on a bicycle, walking, or in a wheelchair), or to make love? The thing which bound these two definitions together is that the disabled person was one who needed help and the professional was there to provide it.

Perhaps the best definition of disability is that it is the condition of a person who experiences discrimination based upon an artificial barrier such as a flight of steps or the ignorance of sign language. Even this definition has its drawbacks as do all the others.

The question remains, however, as to who will make the decisions. The source of the conflict is the use (by professionals) of either a medical model (relating to impairments) or a rehabilitation model (relating to employment). Based upon Talcott Parsons' sick role, these two models both locate the problem within the disabled person and require that the disabled person follow the orders of the professional and recover. The problem with all of these models is threefold.

First, most persons with a disability will never 'recover.' As a wheelchair user because of polio at an early age, I will never cease to need some aid in moving about and therefore will never 'recover.'

Second, by locating the problem within me, the models ignore that my environment contains the barriers confronting me. The environment is what needs changing.

And, third, by requiring that I follow the suggestions of a professional until I 'recover' (and during this time I am exempt from social responsibilities), I am placed in a perpetually dependent position in relationship to the professional.

The medical model and the rehabilitation model produce what some people call the Jerry Lewis Syndrome. Disabled people have a role in society, but only the role which the so-called able bodied minded people define. This Syndrome produces such disability pornography as telethons (hence the name for it) and instills the view of disability as a tragedy. Opposition to these models and their results can be offensive only to parasites who live off disabled people by keeping them subordinate and dependent. These parasitic professionals must also feel superiority (moral and intellectual) in relationship to the tragic, dependent person with a disability.

Many professionals are not aware of the implications of the model which they use. It is the way in which they were trained or socialized into their profession. Their profession gives them a place in society and a means to pay the rent. Knowing this to be true, in my Disability Studies courses (in a graduate public administration program), after discussing the several definitions of disability and their implications, I tell the class that there is a question I am sometimes asked: if someone were to offer me a pill which I could take and I would no longer be disabled, would I take it? I reply, no. Most of the class is either shocked or puzzled.

At that point I single out a woman student and say the following, "I want to ask you a question. After you answer you can hang me out the window by my thumbs if you wish, but please answer it. If I told you that I had a pill and if you took it, you would turn into a man, would you take it?" Usually the student (and others in the class) protest that being a woman is neither worse nor better than being a man, it is just different. My point, I tell them, is the same. For me, being disabled is neither worse nor better than being non-disabled, it is just different.

Many other persons with a disability would answer in another way. One woman in California who said that she would die in about five years at the age of 28 said she would take the pill, but it was death, not disability, which she wanted to avoid. Many persons with disabilities would like to change parts of their life relating to their disability, but many non-disabled persons also want to change parts of their lives.

My point is that for me, and for many disabled persons, my disability is an integral part of my life. I can hardly imagine what my life would be without my disability. At the same time, being disabled is no reason for other persons to treat me in a harmful manner. In the United States (and I can infer in the United Kingdom, New Zealand, Australia, and many other nations) disabled people are devalued and treated in an oppressive way. We tend to internalize that oppression and feel guilty for it. We then begin to act in a way which legitimizes the oppression and the cycle continues.

There are ways in which the cycle can be broken. One of the best ways—and here Barton and I agree—is political activism. If disabled people are to survive we must be politically active. We must seize control of our lives and make the decisions which govern our existence. These decisions are both personal ones and social ones embodied in policy established by the political system (broadly understood). In many localities in the United States we have done just that. We have established that persons with disabilities are entitled to the same resources and opportunities that persons without disabilities are entitled: a good education, access to needed parts of society, health insurance, mobility, housing, recreation, respect, and many other things. It is my hope that my disabled brothers and sisters in other countries have done and can do the same.

There is another avenue by which to attempt to break the cycle of devaluation, oppression, and guilt. Disability Studies courses could be a part of the education of rehabilitation professionals. Courses which discuss the definitions/models of disability and the implications of each would be a starting point. However, discussion alone will not be sufficient. In some way the rehabilitation professional must come to understand the perspective of the person with a disability. The rehabilitation professional must live within the skin of the disabled person. It is a most difficult thing to do and even many persons with disabilities never accomplished the feat, but it must be done.

The successful result would produce a tension within the rehabilitation professional. On the one hand, the rehabilitation professional would plan a course of action to assist the disabled person. On the other hand, the disabled person would have a veto over following it. On paper, in the Individual Written Rehabilitation Plan (IWRP) as it is called in the United States, that is what happens. In reality the rehabilitation professional too often views the reluctant disabled person as manifesting a lack of adjustment if he/she does not view available options in the same way as the professional. The rehabilitation professional must defend the IWRP to her/his superior.

If the rehabilitation professional can not endorse it because of professionally based reservations, the tension can be overwhelming and defeat the IWRP. At the same time, if the disabled person can not endorse the IWRP, then the plan will fail.

It is the rare rehabilitation professional who can invest the emotional energy and the time in devising an IWRP acceptable to each and every disabled person in a caseload. There are days and even months when nothing seems to work. But the same is true for persons with a disability and even for persons without a disability. A thorough understanding of the perspective of the person with a disability does not guarantee success, but the lack of understanding leaves it all to chance.

In conclusion, let me cite one of my favorite authors. According to Nietzsche, people are human only to the extent that we can define our individual self and our relationship with other persons. But the way in which disabled persons are treated means that we are expected to conform to the other person's definition—especially the attitudinal, sensory, and architectural barriers put before us which are based upon that definition.

We are expected to always be cheerful (no matter what). We are expected to put forth a rationalization of how satisfying life is for us (because non-disabled persons can not imagine how we can bear our existence). We are expected to openly accept the non-disabled person even when that acceptance is not reciprocated (when people avoid us, fire us, ignore us, exclude us from society with barriers).

To the extent that we must accept the definition put forth by non-disabled people, we are not human. But we are human and we have a rightful place in society. We must never cease to fight for our rights and our lives. That is the message which the Barton, Ballard and Fulcher chapters contain.

Hugh Gregory Gallagher

Hugh Gregory Gallagher, writer and consultant, is the author of By Trust Betrayed, Patients, Physicians, and the License to Kill in the Third Reich *(Henry Holt, 1990), and* FDR's Splendid Deception *(Dodd Mead, 1985). Gallagher conceived and drafted the Architectural Barriers Act of 1968, the first national disability rights legislation. He uses a wheelchair because of paralytic polio contracted in 1952 and lives in Cabin John, Maryland.*

Professor Barton is not pleased with the impact of Thatcherism upon British social policies. Comment on this aspect of his paper I will leave to his fellow citizens. As a disabled American who has been politically active in the American system for more that three decades, I will address my comments to the social and political perspectives of disability as they are presented in Barton's paper.

I am troubled by the underlying proposition of Barton's piece. Speaking in the socio-political context, he sees disability as "a form of oppression" and he equates this oppression with "being powerless and worthless in an alien society." This strikes me as overdrawn and inaccurate. "Oppression", "worthless" and "alien" are strong emotive words. It seems to me, to the extent these words are *generally* reflective of the feelings or experience of disabled people—and I would argue they are not—they should be understood, in large part, as projection on the part of disabled people themselves.

There is a potential here for confusion. The social, political role of disabled people in society is one thing. The impact of disability upon the individual is another. A disabled person has feelings of grief, anger, and inadequacy generated by his loss or impairment. Unless identified and acknowledged, these feelings may seriously distort the disabled person's view of social reality. This may be what is happening here.

It is Professor Barton's view that society is controlled by "the enemy", who is driven by "excessive individualism" and determined to impose conservative values on family life, women's rights, and disabled people. In opposition to the 'enemy' stands Barton's side — the guys wearing the white hats — "those of us" committed to a "truly democratic society". Barton's side calls for a radical new society, constructed along lines only dimly sketched. In this new society, matters of education and health and social equality would be resolved outside the political arena.

I would argue that the recent advances in the socio-political situation of disabled people in the United States has come about *precisely* because the disabled community has accepted the fact that matters of education, health, and social equality are indeed political issues. The disabled community has determined to play its part as a full and *participating* member of the American political society, as it is. With a new political sophistication, and a dawning awareness of the effectiveness of the political weapons at its command, the disability community has been remarkably successful at working major socio-political change. In practical political terms, disability is a wedge issue: properly framed it cuts across liberal/conservative; Democratic/Republican lines. It was no accident that the sweeping new *Americans with Disabilities Act* was sponsored by both liberal Democratic Senator Kennedy and conservative Republican President Bush.

Disability is part of the human condition; no life is untouched by it. Unlike issues of race, gender, or wealth, disability is not so much a matter of 'us' against 'them'; rather, it is more a matter of shared experience. With consciousness raising, awareness training and education, disability groups have become an effective force for social change. Of course, bottom line, we are talking about the allocation of scarce social resources. Perhaps, today's American society with its individualist tradition, its collapsing values, conflicting demands, overwhelming needs, and astronomical debt can be seen as a vast playing field with many worthy, yet competing teams at play. And if so viewed, it must be admitted that in recent years the disability team has done very well at the game.

A Rejoinder

Len Barton

At the outset I wish to express my thanks to each of the contributors to this monograph for the time and thought they have given in reading and commenting on my paper. They have pointed out some of the limitations of my analysis and provoked me to re-examine some of my arguments. It has been a salutory experience and has reminded me once again that the question of disability is both complex and contentious.

An important point which arises from the reading of the responses is an awareness of how different historical and cultural contexts can lead to misunderstandings and different interpretations when attempts are made to develop comparative insights. I would like to respond briefly to some of these, and try to clarify specific features of my perspective. In doing so, I do not wish to raise questions about the quality of particular responses or give any single one more prominence. They all raise some important issues and offer significant insights, as well as illustrate the varied nature of the views held by both disabled and able-bodied people. Criticism and debate, as we are all aware, are essential ingredients in the change process.

My paper is essentially explorative. It attempts to reinforce the importance of developing alternative frameworks to the medical and psychological models which have so powerfully shaped policy and professional practice in Britain. This is a difficult enough task in such a brief paper because many issues can only be touched on, and there is always the danger of superficiality. There was no intention on my part to provide answers to specific questions relating to change, nor any attempt to offer a comprehensive program for action. This would demand a very different paper and one that I do not feel qualified to undertake.

A key issue is that of the politics of definition. I support those disabled people and their organizations who are opposed to the World Health Organization's definitions of handicap, disability and impairment, and support a social oppression theory of disability. Thus, disability is:

"... the disadvantage or restriction of activity caused by a contemporary social organization which takes little or no account of people who have physical impairments and thus excludes them from the mainstream of social activities" (UPIAS 1976, pp. 3-4).

This definition recognizes that the kind of society disabled people live in will fundamentally influence the way the experience of disability is structured (Oliver, 1990).

An account by Popperwell (1991) vividly captures this type of perspective:

"We use the phrase disabled people to make a statement that the 'disability' is not our problem, it is something that is thrust upon us by society. I refer to myself as a disabled person to make a statement, a political statement about the oppression that I experience, to show that I am not a poor tragic individual, rather that I am part of a group who share a common oppression. For me to define myself as a disabled person is a very empowering thing. It has meant that I have come to see my position in a wider context, it is no longer my fault and it describes the constant discrimination I face" (p. 2).

I am not advocating that all disabled people share this viewpoint, but increasing numbers *do* subscribe to it, and it is the accepted terminology of the *British Council of Organizations of Disabled People*. It unreservedly defines disability in political terms. This is not therefore just a question of semantics.

A central assumption underpinning this approach is that to be disabled means to suffer; to be discriminated against. Pride and dignity on the part of disabled people needs to be understood in relation to an essentially oppressive and offensive society. The stubbornness and extent of institutional discrimination has been most powerfully demonstrated in a study "conceived, sponsored and written with the full cooperation of disabled people and their organizations," (p. ix, Barnes, 1991). Enns, the writer of the foreword of this book highlights the gravity of the situation in Britain:

"This book provides hard and solid data ... that disabled people in Britain are in fact worse off than those in many developing countries. This is indeed a harsh reality that many are reluctant to face. Nevertheless, one needs to accept the facts if change is to be made" (p. vii).

Since the publication of this book, attempts to introduce anti-discrimination legislation in the UK have again failed, thereby reinforcing the seriousness and urgency attached to these issues.

Some respondents feel that I am opposed to efforts for incremental change or that I underestimate the advances that have been made resulting in benefits to disabled people. This would be to misrepresent my position. My argument is that we must keep before us a wider vision and a recognition that if 'independence' and 'participation' are to have lasting effects then more fundamental changes will ultimately be required. This will involve challenging the power-base and control of professionals. Few disabled people in Britain are in professional positions offering the sorts of role-models that are essential features of effective change.

Experiencing life in another culture enables one to appreciate that social conditions and relations are changeable and this was clearly brought home to Finkelstein (1990) on a visit to New York. He describes the benefits of using accessible transport in contrast to his experience in England:

"In New York travel on public transport gave me an opportunity to share an important daily activity with other commuters. For the first time in adulthood, I felt I was experiencing the same freedom of movement as my able-bodied peers" (p. 7).

The mutual ignorance of different national disability organizations, campaigns, literature and relevant research findings needs to be addressed. Hopefully, this monograph will provide some references to be investigated and as well be a stimulus for further discussion and networking. I would welcome correspondence with any interested parties on these issues.

Finally, there is still a great deal to be done. None of us have any grounds for complacency. Whilst anti-discrimination legislation is essential, it is not in itself a sufficient condition for the wholehearted inclusion of disabled people in all segments of life. Millions of disabled people are living on or below the poverty line and many of these are in advanced industrial societies. We are still a long way from achieving fully inclusive societies. The unequal treatment accorded to disabled people, as well as to other minorities, is unacceptable. For this to be effectively addressed it will necessarily involve viewing disability as a political issue, one in which human rights is a central concern.

References

Barnes, C. (1991). *Disabled People in Britain and Discrimination: A Case for Anti-Discrimination Legislation*. London: Hurst & Company and University of Calgary Press, Canada.

Finkelstein, V. (1990). 'A tale of two cities' in *Therapy Weekly*, Vol. 16, No. 34, pp. 6-7.

Oliver, M. (1990). *The Politics of Disablement*. Basingstoke: Macmillan Education Ltd.

Popperwell, L. (1991). 'More Than Just Words' in *Avon Coalition of Disabled People The Voice of Disabled People in Avon*. Bristol. Issue 5.

UPIAS (1976). 'Fundamental Principles of Disability' London: Union of the Physically Impaired Against Segregation.

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